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Negotiating and Navigating Invisible Food Deserts: An Exploratory Study on Foodways of Adults on the Autism Spectrum

Jung Ja Park Cardoso
The Graduate Center, City University of New York

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NEGOTIATING AND NAVIGATING INVISIBLE FOOD DESERTS:
AN EXPLORATORY STUDY ON FOODWAYS OF ADULTS ON THE AUTISM
SPECTRUM

by

JUNGJA PARK CARDOSO

A dissertation submitted to the Graduate Faculty in Psychology in partial fulfillment of the
requirements for the Doctor of Philosophy, The City University of New York

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Negotiating and Navigating Invisible Food Deserts:
An Exploratory Study on Foodways of Adults on the Autism Spectrum

by

JungJa Park Cardoso

This manuscript has been read and accepted for the Graduate Faculty in Psychology in satisfaction of the dissertation requirement of Doctor of Philosophy.

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THE CITY UNIVERSITY OF NEW YORK
ABSTRACT

Negotiating and Navigating Invisible Food Deserts:

An Exploratory Study on Foodways of Adults on the Autism Spectrum

by

JungJa Park Cardoso

Adviser: Professor David Chapin

I explored foodways of adults on the autism spectrum in order to understand how they negotiate and navigate their food environments. Foodways are beliefs and practices involved in food production, preparation, distribution and consumption (Counihan 2008). In an effort to hear marginalized voices in autism discourse, I conducted an online survey and interviews in modes chosen by participants to accommodate the communication needs of a wide range of autistic adults. The primary participants were highly educated adults with a formal autism diagnosis \( n = 23 \) and self-diagnosed adults \( n = 6 \). Out of the 29 autistic participants who completed the survey, eight participated in online interviews or in-person interviews. I also conducted a supplementary online survey and interviews with three parents of autistic adults. Participants’ beliefs about needing certain diets to treat or ameliorate autism were related to their conceptions of autism, and they described their food environments as invisible food deserts, where access to food that may benefit health was limited because their autism-related characteristics were not accommodated. The characteristics of the invisible food deserts included limited availability of edible foods due to restricted diets, ‘unsafe’ people who enforce unwanted social interactions or diets, prevalent over-stimulating food places and hours of operation experienced as restricted. Negative experiences of the invisible food deserts were often exacerbated by limited financial
resources, difficulty in asking for changes or help, limited mobility due to lack of driving skills and challenges in cooking and growing food. To survive in invisible food deserts, they used various coping strategies, which I categorized as avoiding the source of inputs, blocking inputs, and maintaining distracted focus. Some of the strategies entailed concerns and costs. I discuss implications for a food environment that is friendly to autistic adults and suggestions for future research.
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This dissertation would not have been possible without my research participants. Each of your understandings of autism is widely different from each other. But you all shared one thing—generosity, which deeply touched my heart. You all kindly shared your time and insights with this amateur researcher, believing in the value of research that may contribute to the creation of food environments that are friendly to adults on the autism spectrum. My special thanks go to Mastermind and his mother. You kindly opened your arms and door of your house and invited me into your life with autism and beyond. You shared life stories, tears, laughter, and food with me. I would never forget our time together. We will continue our friendship and conversation. Mastermind, you really played a role of The Mastermind, like your chosen pseudonym, helping me revise my research materials. And, my dear friend, Drew! You inspired me to study this topic and generously shared your life stories with me as a friend and participant and a translator between autism world and non-autism world. I also thank those who helped me spread the word about my research by forwarding my recruitment flyers to their networks or posting it to their websites and social media: Kate Palmer, President of the Global and Regional Asperger Syndrome Partnership (GRASP), Alyssa Hillary, Lydia Brown and Jason Ross, who are members of Autistic Self Advocacy Network (ASAN), Pat Schissel, Executive Director of Asperger Syndrome & High Functioning Autism Association (AHA), Amy Goodman, Co-director of Autism NOW at The Arc, Ali Watters of Autism Speaks, C. S. Wyatt, author of The Autistic Me blog, and some Yahoo autism group leaders. Your kind help meant so much.
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I am deeply grateful for my dissertation committee. Professor Barbara Katz Rothman has helped me untangle my research interest in medical sociology, disability studies, public health and food studies from the inception of this project. My interdisciplinary dissertation work would not have been possible without your guidance. And, thank you so much for always kindly being there whenever I needed your help. I also thank you for assuring me that food studies can be useful in understanding social, political and cultural relationships and that exploratory research is
meaningful. Professor Kristen Gillespie-Lynch is the autism expert that I had dreamed to have in my committee after reading her paper on conceptions of autism. She readily accepted the invitation to be on the dissertation committee and kindly helped me in many stages of my dissertation project. She helped me with narrowing down my research topic, finalizing my survey and interview materials, and distributing recruitment flyers, and provided thorough feedback. Your kind help and guidance was greatly appreciated. I offer deep appreciation to Professor Christina Nicolaidis, for happily accepting the invitation to be a reader after reading my preface, giving me thorough feedback on the long draft, and sending me helpful sources. Her participatory research approach is a model for me to follow. I thank again President Kate Palmer, who was much more than a reader. She reviewed my survey and interview materials, assured the importance of my work, posted the recruitment flyer on the GRASP’s website and Facebook page, and served as a reader bringing her unique perspectives as an autism self-advocate, psychologist and former chef.

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PREFACE

For a more objective study, a researcher should be unbiased and should not try to impose one’s value or opinion onto the research participants while conducting the research. However, it is an inevitable truth that any researcher is a product of the person’s experience and learning and the society that influenced those, and the researcher’s study is guided by these influences in every step—deciding research questions, theoretical frameworks, research methods, etc. Presenting this dissertation as though it was conducted in a value-free vacuum would be less objective and less scientific from a perspective of the feminist research tradition. Here I disclose my history, values and attitudes, to my research participants and readers of this dissertation, telling how this research began and how the journey has been.

By living in the U.S. as an international graduate student and thus having some difficulty in communication and socializing, I caught a glimpse of life on the autism spectrum. The language—both spoken and body—and the culture in this new land were different from my native ones. Idiomatic expressions went over my head. I constantly felt anxious while trying to make sure I understand, speak and write correctly. At the beginning, there was even a moment when people were talking among themselves in a room as if I was not present there because I was quiet, just processing what I was hearing. I wanted to engage but I couldn’t. There were also many unwritten rules that must have been obvious to others but not to me. Only thinking about Americans being punctual, I arrived too “on time” when a professor threw a house party for students, while others came at least 10 minutes late and some were fashionably late by more than 30 minutes. The professor was still busy preparing for the party. I became constantly conscious about whether my behavior was culturally correct. Making friends was difficult. I often felt lonely. All these everyday struggles and uncomfortable feelings were not something I
experienced often when I lived in my home land. When I had received an almost perfect TOEFL score, I didn’t imagine that living and communicating here would be a quite different story from having a high English test score. However, as autistic people develop constantly at their own speeds and ways, I have constantly developed at my own speed and in my own way. I was once an international student who did not even open her mouth during the class but now a professor who observed my lecture wrote in an evaluation that I am “distinctly superior to most Lehman teachers that [he had] observed.” I am developing just differently.

Because I had some understanding of what it is like to live as an “atypical” and feel often uncomfortable, I have been interested in creating a respectful and safe space. The professor who observed my lecture asked me how I could engage my students that well. I shared some tips such as asking students to upload their portrait photos to the online Blackboard and memorizing their faces and names by the second class, and using examples from their everyday life while giving a lecture. An answer I happened not to share is “Because I was there.” I was one of those students who are shy. Because I had been there, I told my students that our class is a mutually respectful and safe environment and that there is no stupid questions and stupid answers. In an environment where one feels respected and safe, the person thrives.

While both autistic individuals and I live in a “foreign” land and are different from the “natives,” I’m also widely different from autistics. I was not quite there. Many autistic people grew up without an autism diagnosis and did not know the reason why they did not fit in; they did not know that it was because they are autistics who live in a non-autism land that is largely designed for non-autistic people. They could not find those who understand them. When they were not diagnosed, they heard they are simply wrong. When they were diagnosed, they heard autism is wrong. In contrast, I knew why I am different from people around me in this land; it
was because I voluntarily uprooted myself and transplanted myself here though I didn’t quite know what it would be like. I knew where I can meet people who are just like me and where I can fit in without much effort. People in this land neither say I am intrinsically wrong for being a Korean nor for being a woman. I can’t fathom what it is like to live on the autism spectrum.

In addition, I am not particularly sensitive to environmental stimuli, though I have noticed that their effects on me are stronger when I am under stress such as when I have to process and use my new language or when I am in an unfamiliar social setting. Before learning about Asperger’s syndrome and sensory issues related to it, I did not understand why my friend Drew, who unbelievably endured pain from a broken tendon, was that frightened and mad when gently poked by me. I did not understand why this grown up friend is still a picky eater and fears needles like a child. I did not understand why this good friend with genuine heart and humor would suddenly become that hostile to me or disappear when we are in stuffy, noisy, crowded and/or brightly lit places. There was a time I thought about ending our friendship because I was too frequently perplexed by this friend. When I happened to read about Asperger’s syndrome, my eyes were opened. That was truly enlightening to me, who was full of prejudice. Before learning about Asperger’s, I thought the friend is self-centered and lacks empathy. Now I knew it was me who was self-centered and lacked empathy. I had judged without knowing. When I read a part of the 108 Prostrations of Great Repentance below to the dear friend, the response was “Oh, yes! You need to repent”:

I prostrate in repentance for having thought that only what I saw was correct.
I prostrate in repentance for having thought that only what I heard was correct.
I prostrate in repentance for having thought that only what I smelled was correct.
I prostrate in repentance for having thought that only what I tasted was correct.
I prostrate in repentance for having thought that only what I felt was correct.

I prostrate in repentance for every action born from I-my-me mind.

As a way of repentance, I embarked on this long journey of learning how adults on the autism spectrum experience and respond to their environments; particularly their food environments because my friend Drew had issues with food and getting food. I wanted to contribute to changing our food environment to one that is friendlier to them where they can feel welcomed, respected and safe. This dissertation is a process of my repentance. It is not just for my degree. I have poured my heart on this research. My previous advisor had said he would not be able to advise me unless I have another committee member who has expertise on autism. While there were many professors who have expertise on autism, it was difficult to find someone who balances between medical model of autism and social model of autism; for current autism discourse is dominated by medical model of autism. I could have given up this topic because having an advisor is the very least requirement for dissertation research. Developing a dissertation committee alone took a few years for me. But I still stuck to this topic to the point where even Drew said I’m obsessed with this research and I need to become like a “professional, who does not give a heart, does not think about the consequence, just gets it done, gets the money, and goes home and forgets.” Though Drew does not like people who have such a “professional” attitude, Drew suggested I should just work on any topic for my degree, and do whatever research I want only after I graduate and get tenured, saying that receiving a doctoral degree is like getting a driver’s license: “You can go anywhere after getting your driver’s license. You get a driver’s license just to show that you know how to drive. It doesn’t matter in which
course you practiced. You want to drive along a beautiful coast? Drive there after getting your driver’s license.”

The course I took was spectacular but it was long and bumpy. Because autism is not even well defined, doing research on people on the autism spectrum was like driving on a road that has not been paved yet. It was also confusing. Surrounding this controversial diagnosis, there were many sign boards that were pointing at different directions. There were many different voices about autism and their voices were all correct, based on their experience, as a mother of an autistic adult son and autism expert said. She explained the difference in opinion about autism using the Indian parable about the blind men and the elephant (Sicile-Kira & Sicile-Kira, 2012):

A group of blind men touch an elephant to learn what it is like. Each one feels a different part, but only one part, such as the leg or the tusk or the trunk. Each one describes and names the elephant based on his experience of the part of the elephant he is feeling. Such is the nature of autism.

The parent of a teenager who is nonverbal, not toilet trained, and experiences meltdowns will never be convinced that autism is just a brain difference to be accepted. The parent of a young child who appeared perfectly healthy and then regressed at age two and has terrible gastrointestinal problem with ongoing daily bouts of diarrhea or constipation may consider autism a disease. On the other hand, the parent of a child with Asperger’s who is independent and academically brilliant may view autism as a gift. The point is they are all correct, based on their experience (Chapter 1, The history and future of ASD section, Autism as neurodiversity sub-section, para. 2 and 3).

Many times my fingers just hovered over a key board while I was deciding when to use ‘autistic person’ and when to use ‘person with autism’ because these words are accepted differently
depending on one’s understanding of autism, which is largely shaped by one’s experience of autism.

In the middle of the journey, I took a side track when I learned more about health issues common among people on the autism spectrum, which I also don’t have. Most of those health issues were chronic ones whose root causes cannot be cured by conventional medicine, such as gastrointestinal conditions, allergies and sleep problems. I started spending more time reading about these conditions in the context of autism and I even took a leave of absence to take prerequisite science courses to enter an alternative medicine school. I was enticed by the concept of care, not cure, of oriental medicine, particularly that of a medicine called Eight Constitution Medicine. It categorizes people’s congenital body constitutions into eight types without pathologizing any of the types, and prescribes ways to take care of one’s health mainly using foods that accord with one’s constitution type, which keeps one’s unique congenital imbalance and avoids extreme imbalance that may cause illness. I resumed my Ph.D. studies in environmental psychology, after realizing that this approach to medicine does not concern environmental aspects that may influence what people experience while accessing food, and my research may contribute to deepening our understanding on how autistic people experience and respond to their food environment. But the approach and philosophy of the medicine is deeply engraved in me.

Driving a long and bumpy road without a driver’s license was difficult, but I believe the findings of this research is meaningful and valid because this research was done with great passion of an amateur and true “experts.” Once I become a professional, for a while I might not have freedom to choose which research I want to conduct. I will have become more skillful, hopefully, but I might not have passion and time as much as now. When asked to make critical
comments on my online survey, one participant wrote, “Honestly, not that well done. It's obvious that you're an amateur...” By amateur, she obviously meant being inept. But the person closed her comment with “but it's better than other surveys I've taken.” If other surveys she took were developed by professionals and her comment was written in a neurotypical way, the comment could have been “This survey is better than the ones developed by professionals.” Because I poured my heart on this research like an amateur, I was able to involve autistic friends and autistic people who became my friends while I was planning this research. That helped developing a “not that well done...but better than others surveys.” One autistic participant noticed this effort and commented: “this survey was much more professional than I thought it would be. The topics were spot on...it's almost as if someone autistic wrote it...I [am] very impressed. It takes a lot to impress me.” Even though I was an amateur, my autistic partners and participants were experts of their own autism and we together produced this dissertation.

While my research findings may benefit people on the spectrum sometime later, some of my research participants seemed to have enjoyed the participation process itself. While revising my research materials together with me and learning that his voice is important and needs to be heard, Mastermind said, “Tonight is one of the happiest times in my life. I’ll never forget this time.” He had previously said everyone is his enemy and he considers himself to be on the autism spectrum because he feels he is like “an outcast of society.” I felt moved when he later asked me if he may call me ‘apu,’ which means older sister in his parents’ mother tongue. Another participant said, “This survey was a lot of fun! I never had a place to share my food issues, so I appreciate this outlet.” I received positive responses from those who did not participate as well. When I shared some of my research findings with a lady while helping her navigate an online group using her tablet PC, she said that her husband, who is diagnosed with
Asperger’s after he was retired, is like a Dr. Jekyll and Mr. Hyde. She later emailed me, “… you restored the compassion and understanding factor balance to me. So good to talk together….
Thank you for invaluable lessons on life and computer! And good to get to know wonderful you.” I felt I am now more connected to people in this foreign land, whether they are on the autism spectrum or not, and my long years of research endeavor is bearing fruits of compassion and understanding. I hope seeds from these fruits spread and bear fruits wherever someone’s life is colored with autism.

As I often played a role of a mediator between Mastermind and his mother, I also hope this dissertation becomes a middle ground where we all meet to deepen our understanding of each other and make this world friendlier to people on the autism spectrum. I invite you to the record of my journey.
CHAPTER I
INTRODUCTION

Problem Statement

Adults on the autism spectrum have a higher rate of major psychiatric and medical conditions compared to those not on the spectrum (Croen et al., 2015). Accordingly, studies on health-related quality of life among adults on the autism spectrum have revealed lower physical, psychological and social health status, as compared to the general population (Khanna, Jariwala-Parikh, West-Strum, & Mahabaleshwarkar, 2014). While there is no “cure” for autism, the medical community widely prescribes drugs for commonly accompanying symptoms of autism, such as anxiety, depression, obsessive compulsive disorder, sleep disorder, and gastrointestinal conditions, despite the high cost and numerous side effects of medication (Lawton, 2007).

Objecting to the quick fix pharmaceuticals offer, an autism self-advocacy group, the Global and Regional Asperger Syndrome Partnership (GRASP), stated the following:

[S]imple notions of diet, exercise, or a change in environment could likely eradicate the need for a high percentage of the pharmaceuticals our community takes. Because of our busy lives, folks sadly find it easier to take a pill than commit to such changes [emphasis added].

This statement implies that autistic individuals need something that will support their desired behavioral changes for health. Since the environment is one of the important factors that influence health and health behavior and the built environment is a source of environmental stimuli, to which autistic individuals are often sensitive, it is critical to understand how individuals on the autism spectrum perceive and experience certain environmental settings and situations as problematic or supportive for them with regard to health.
Background

Definition and treatment of autism has been dominated by the medical model, which pathologizes atypical behaviors of people on the autism spectrum. It presents autism as a deficit to be cured. The medical model of autism has been more recently challenged by scholars and vocal autism self-advocates. They approach autism through the social model (Robertson, 2009), which views the society as the source of disabling barriers (Oliver, 1990). Aligned with the social model of autism, the majority of autistic adult self-advocates seeks support for quality of life rather than medicine for “cure” of autism spectrum disorder (Robertson, 2009). Autistic self-advocates generally adopt a neurodiversity perspective, viewing autism as natural human variation with strengths as well as weaknesses (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2012). The proponents of this perspective advocate that autism constitutes their core essence, which they relate to their neurological, qualitative difference from “neurotypicals” (NT) (Nadesan, 2005).

Noting the tensions between the medical and the social models of autism, or pro-cure and anti-cure agendas, Silverman (2008) suggests scholars overcome taking a fixed position within either model. She states that taking a fixed position has limitations in influencing the ways that societies handle the issues of accommodation for autism. A critical examination of the original meaning of “cure” and the context in which its meaning has been changed provides an insight in going beyond debates over pro-cure and anti-cure agendas. According to historians of biomedicine, the original meaning of “cure” is “to take care of the ill (make them feel better)”, not “to remove the disease entity” (Halliburton, 2009, p. 166). The current meaning of “cure” reflects “the tendency in modern medicine (allopathy/biomedicine) to utilize invasive procedures to remove any abnormality” (as cited in Halliburton, 2009, p. 166). Since the original meaning of
“cure” is not in use now, it would be inappropriate to use the term “cure” to mean “to take care of” without an explanation to avoid confusion. Nevertheless, this etymological meaning of “cure” suggests involved parties redirect their focus from debating over pro-cure and anti-cure agendas to challenging inappropriateness of invasive procedures of modern medicine and requesting for truly health caring systems. I believe stress-reducing environments that promote health should be an imperative part of such systems.

Built environments are known to significantly shape health-related behaviors of individual dwellers. Accordingly, many design and planning decisions have been suggested as public-health decisions (Wells, Evans, & Yang, 2010). Environmental factors that structurally engender unhealthy behaviors related to obesity, for example, have been examined, and design and planning strategies to improve dietary behavior and physical activity have been intensely discussed (Booth, Pinkston, & Poston, 2005). In contrast, growing research interest in built environments for individuals on the autism spectrum, which is another major “public health concern” according to health authorities (Centers for Disease Control and Prevention (CDC), 2015), does not consider environmental surroundings that would influence dietary behavior.

Given that the built environment influences health behavior—and diet is one of the important factors that influence health issues that are associated with autism—further research is necessary to examine how built food environments support or fail to support autistic individuals’ desired healthy foodways. According to Counihan (2008), foodways are the beliefs and practices involved in food production, preparation, distribution and consumption. Examining foodways and the built food environment together has been suggested as a better way to understand health disparities because food environments and foodways shape each other (Cannuscio, Weiss, & Asch, 2010). The built food environment may be designed to play a positive role in ameliorating
various health issues associated with autism when foodways and the built food environment of autistic individuals are studied together.

**Purpose of the Study**

This dissertation research aims to explore how adults on the autism spectrum negotiate and navigate the food environment. This research particularly seeks to answer how certain environmental settings and situations are considered problematic or supportive in relation to everyday foodways: the beliefs and practices involved in eating food, going grocery shopping, growing food, and cooking. The methodological significance of this study is the use of online research methods, which is a useful way to hear the voices of autistic individuals who find online communication easier than face-to-face communication. This research develops and analyzes findings from an online survey and online/offline one-on-one interviews.

The findings of this study—representing the voices of autistic participants—may contribute to the development of food environments that are friendly to individuals on the autism spectrum that accommodate them, promote their health and respect their conceptions of autism. Autism-friendly food environments would be also beneficial to the general population who are not diagnosed with autism for various reasons but experience similar challenges. I raise questions regarding food environments in order to challenge society’s limited approach to autism, which has targeted individuals (Nadesan, 2005). This study also may contribute to the emerging literature on the notions of autism friendly environment and person-environment fit in the context of autism (Lai & Baron-Cohen, 2015)
Chapter II

LITERATURE REVIEW

This literature review will be organized into the following four categories: 1) socially constructed medical knowledge of autism, 2) cultural meanings attributed to autism, 3) lived experience of autism, and 4) food environment, foodways and autism. Medical knowledge of illness, illness experience, and cultural meanings attributed to illness are socially constructed, according to the social constructionist perspective, which is based on a theory that the social phenomena that appear natural or inevitable are reflections of a particular society at the particular historical contexts (Conrad & Barker, 2010). The social constructionist approach’s emphasis on social dimensions of illness does not necessarily mean that it rejects a biological dimension of illness. As a way of approaching the social construction of autism, Nadesan (2005) took a moderated social constructionist approach that views illness in terms of “the interaction between biology and cultural practices and interpretive frameworks,” which is differentiated from an extreme constructivism that views illness as “purely socially constructed or is an unknowable facticity rendered intelligible only through its various socially constructed representations” (p. 181). She points out that the dialectical approach which emphasizes the interaction of biology and culture requires reconciliation of Cartesian dualisms of mind-body or biology-culture. The cultural practices, she explains, such as “diet, architecture, and comportment” provide social conditions that may “produce particular kinds of bodies” (p. 182).

In the first section of this literature review, I review literature on how medical knowledge of autism is socially constructed, and introduce the idea of autism and some characteristics of biomedicine, which have marginalized environmental dimensions of autism in autism discourse. The section on cultural meanings attributed to autism reviews debates over whether autism,
especially Asperger’s syndrome, is a disability or difference, and discusses issues regarding disclosure of autism. The section on lived experience of the autism spectrum is largely based on personal accounts of autistic individuals, which give insights on ways to balance cure of autism and acceptance of autism, life with sensory sensitivity issues and limitations of behavioral therapies. In the last section, I review literature on the built food environment and foodways in relation to autism and health.

Socially Constructed Medical Knowledge of Autism

Answers to what autism is vary because autism is heterogeneous in terms of symptoms and etiology and because the biomedicine system constantly widens the boundaries of abnormalcy and illness (Nadesan, 2005). Autism is a general term for a behaviorally defined range of neurodevelopmental characteristics that is pathologized as autism spectrum disorder (ASD) in the early twenty-first century biomedicine. The current criteria of autism spectrum disorder (ASD) are deficits in social communication and social interaction, restricted, repetitive patterns of behavior, interests, or activities, and sensory processing difficulties (American Psychiatric Association (APA), 2013). The diagnostic criteria of autism have been constantly changed, which suggests that the idea of autism is socially constructed.

Medical knowledge of autism (i.e., diagnostic criteria, etiology, and remediation) is influenced by philosophies and practices of biomedicine. Biomedicine is a widely used term in medical anthropology to refer the dominant “Western” medical system (Baer, Singer, & Susser, 2003). Hahn and Kleinman, who popularized the term, used it for the medical theory and practice of Euro-American societies because their medicine primarily focuses on “human biology, or more accurately, on physiology, even pathophysiology” (Hahn & Kleinman, 1983, p. 306). Pathologization is a tenet of biomedicine. Changes of environmental factors of a “disease” are
rarely used as a treatment for the pathologized condition in biomedicine. Some of characteristics of biomedicine related to autism are medicalization, geneticization and physical reductionism and mind-body dualism.

**Medicalization of autism.** Many ordinary human conditions have been absorbed into the domain of professional biomedicine through a process that is referred as medicalization (Conrad, 2007). The case of Asperger’s syndrome, a mild form of autism, is telling. In the biomedicine system that constantly widens the boundaries of illness, Asperger’s syndrome has been pathologized as a mental disorder that requires medical treatments.

A historical review of the diagnosis of Asperger syndrome reveals how the syndrome has been medicalized (Nadesan, 2005). In 1944 Viennese pediatrician Hans Asperger identified and described the syndrome as an “autistic psychopathy” form of personality disorder, based on four boys who had autism-like disorders with relatively normal intelligence (Attwood, 2008; Wing, 1981). Asperger noticed that the boys had difficulties in social relations but they also had exceptional talents. Because of World War II and the restrictions of information exchange between opposing forces, he was unaware of an American contemporary, Leo Kanner (1943), whose subjects showed characteristics similar to those of the four boys. Kanner coined the term “early infantile autism” to describe the children who were unable to socially relate to others in what was perceived of as ordinary. They showed extreme autistic aloneness. After Asperger encountered Kanner’s (1943) work, Asperger distinguished the disorder that later bears his name from “early infantile autism,” in that the social skills of the children he described were much better (Asperger, 1979). Asperger’s work was finally introduced to English-speaking countries when Lorna Wing published her essay “Asperger’s syndrome: a clinical account” in Psychological Medicine in 1981. She named the syndrome described by Asperger as Asperger’s
syndrome and argued that this syndrome is a more accurate diagnosis for many psychiatric patients (Wing, 1981). Her article has popularized Asperger’s syndrome and transformed the syndrome he described as a personality disorder into a psychiatric disorder (Nadesan, 2005). Asperger’s syndrome, whose characteristics used to be considered part of normal human variation, was included in the Diagnostic Statistical Manual of Mental Disorders (DSM-IV) in 1994 and the diagnosis was dropped from the fifth edition (DSM-5) in 2013. In the DSM-5, autism spectrum disorder (ASD)—now a single umbrella diagnosis—covers all previous DSM-IV pervasive developmental disorder diagnoses: autism disorder, pervasive developmental disorder not otherwise specified, Asperger’s disorder and childhood disintegrative disorder.

Medicalization transforms “a problem at the level of social structure…into an individual problem” (Waitzkin, 2000, p. 35). Since autism spectrum condition is labeled as a medical condition, numerous interventions at the individual level have been tried. The attempts to ameliorate autism are limited to treating its co-morbid conditions through medication (Lawton, 2007). Side effects of medications for these disorders have been concerns (Foster & King, 2003).

**Geneticization of autism.** As genetics is “increasingly identified as the way to reveal and explain health and disease” (Lippman, 1994, p. 144) and the hereditary basis of autism has been established by research involving twin studies, autism has been geneticized (Bumiller, 2009). Geneticization is “an ongoing process by which differences between individuals are reduced to their DNA codes” (Lippman, 1991, p. 19). By inaptly equating human biology with human genetics, geneticization implies that human genetics “acts alone to make us each the organism she or he is” (p. 19). As autism has been geneticized, even a prenatal genetic test for autism is impending (Bumiller, 2009). In an analysis of prenatal diagnosis as an example of the growing influence of geneticization, Lippman (1991) argues that the “reassurance” of a healthy
fetus, which high-tech genetic approaches claim, would be clearly achieved through “low
technology” towards social determinants of health as well if given the resources allocated to the
high-tech sector. The built environment is one of the social determinants of health. Nevertheless,
our biomedicine-dominated society mainly focuses on searching for ‘susceptible’ genes for
autism and creating gene therapies in addition to pharmaceutical drugs to treat individuals
(Nadesan, 2005).

From the genetics perspective the locus of autism is in “susceptible” genes (Nadesan,
2005). The “susceptible” genes are, however, “‘neither necessary nor sufficient’ to cause disease,
are ‘common within the normal population’ and most importantly, ‘expression of the disease
involves the interaction of multiple genetic and environmental factors’” (Wilkie, 2001: 622, as
cited in Nadesan, 2005: 217). Recent research has suggested that environmental factors play
important roles in gene expressions associated with autism spectrum (Sears & Genuis, 2012).

The concept of ‘susceptible’ genes has been criticized also for “localiz[ing] the
responsibility for disease in the individual”: the concept inadvertently implies that it is the
individual with such genes who is problematic rather than the built environment despite its role
in “shaping and/or catalyzing genetic responses” (Nadesan, 2005, p. 218). By defining the
individual who is susceptible to environmental assaults as defective, genetic approaches obscure
the role of environmental causalities, or environmental defects (Bumiller, 2009; Proctor, 1992;
Rothman, 2001).

Although at least the public health approach is expected to focus on providing safe
environments, it, too, has been dominated by the genetics rhetoric that inherently has focus at the
individual level. Increasing the public’s literacy on genetic technology, including prenatal and
postnatal screening, has become a twenty-first-century goal by public health officials (Bumiller,
In a critical analysis of genetic approaches, Rothman (2001) criticizes ‘public health’ for heavily allocating financial resources to genetic research. She asserts that prevention of cholera, for example, essentially relies on a safe water supply, not on campaign programs to teach individuals to boil water or, identifying the “gene for” susceptibility to cholera for genetic screenings.

**Physical reductionism and mind-body dualism.** Despite the emerging evidence for the systemic integration of our whole body from systems biology in the twenty-first century, reductionism is still prevalent in biomedicine (Hyman, 2010). Hahn and Kleinman (1983) pointed out that physical reductionism in biomedicine radically separates body from nonbody. The dominant Cartesian mind-body dualism of biomedicine (Lock & Scheper-Hughes, 1990) has obscured the new evidence that the brain function is profoundly connected to the function of other parts of the body. For example, the gut, the digestive system with the esophagus, stomach and intestines, is connected to the brain through the vagus nerve, and the gut sends much more amount of information to the brain than it receives from the brain (Gershon as cited in Wang, 2012). Most notably, it is not the brain but the gut that synthesizes about 95% of serotonin. Low levels of serotonin affect anxiety, depression, sleep difficulties, and obsession, which are particularly common among individuals on the autism spectrum. Obsessive interests and behavior are also one of the core characteristics of autism. However, the brain is still regarded as the locus of autism in the contemporary biomedicalized society, where brain-centered approaches to the human person are dominating (Ortega, 2009). Even though a nutritional deficiency or insufficiency may be a factor of variously manifested physical symptoms in different parts of an *autistic body*, the conventional reductionist medicine attempts to treat the different “diseases” with different medications in different medical departments.
**Dietary interventions for autism.** One of Hippocrates’ great teachings is “Let food be thy medicine and medicine be thy food.” Although conventional medical doctors still take the Hippocratic Oath, food as a medicine is ironically rarely practiced by them. Dietary change has been tried as an alternative solution to treat core symptoms and comorbid symptoms of autism when conventional treatments do not seem to treat core symptoms or when side effects of conventional treatments are concerned (Levy & Hyman, 2015). The most famous diet for autism is gluten-free casein-free diet (GFCF diet); gluten is a protein of wheat and casein is a protein of milk (Campbell-McBride, 2010). Avoiding soy, sweeteners, food colorings, preservatives, or taste enhancers is also commonly tried. The health benefit of having organic produce is emphasized particularly for the autistic population.

The science behind these dietary solutions is that many people on the autism spectrum are allergic or sensitive to these foods, food additives and pesticides because they have “compromised” liver function (Bock & Stauth, 2007; Hyman, 2010; Lawton, 2007). The liver that creates glutathione, the main detoxifier and antioxidant, is the center of detoxification. A high level of accumulated heavy metals and other toxins exhaust glutathione. The liver of some autistic people creates a relatively low level of glutathione (James et al., 2004). The presence of accumulated toxins is the primary factor of immune abnormality (Bock & Stauth, 2007), which results in allergic reactions to common food properties, such as casein and gluten. It is also one of the causes of autoimmunity, in which the immune system attacks healthy tissues, such as those in the gut (p. 130). Natasha Campbell-McBride (2010), a medical doctor and nutritionist who advocates dietary treatment for autism and claims her son lost his autism diagnosis, pays attention to the relationship between autism and the damaged gut. Campbell-McBride maintains the damaged gut produces large amounts of mucus that block bile and digestive enzymes, which
are critical in digesting fats. As a result, fat soluble vitamins A, D, E, and K are deficient in a person who suffers autoimmunity. Deficiencies in those vitamins and their symptoms are common among people on the autism spectrum (p. 103-104).

The current practice of dietary interventions for autism, most notably gluten-free casein-free diet, is not without problems. First, processed gluten-free products are not healthy just as their gluten-containing counterparts are not. Campbell-McBride (2010) criticizes the current gluten-free casein-free movement led by food industry. A large portion of processed gluten-free products are, she states, loaded with sugar, refined carbohydrates, unhealthy fats and many other ingredients which autistic individuals must also avoid. She warns that the heavy marketing of unhealthy GFCF pre-prepared foods is lulling people into a false sense of security: “if it is GFCF, it must be fine for my autistic child” (Campbell-McBride, 2010, p. 93). Second, restricted dietary practices have been found to may have negative effects on the general quality of life by creating negative emotions and limiting opportunities for social relationships (Walker, 2013). Research on quality of life of patients with celiac disease has found that quality of life, self-perceived health and mental health decline after many years of adherence to a gluten-free diet although the key treatment had resulted in initial improvements in quality of life (Sverker, Hensing, & Hallert, 2005, p. 172). Having appropriate levels of social interaction is an integral part for health, particularly for individuals on the autism spectrum. Many health problems autistic individuals suffer may be resulted from “feeling like outsiders in society,” according to Lisa Croen, who has studied the health status of adults with autism (Wright, 2014). Croen states, “inclusion and feeling part of society really does impact on health status…It’s very important to include adults with autism in all sections of society” (p. 10). Adherence to a restrictive diet has a
possibility of further socially isolating individuals on the spectrum, with a greater chance that their health-related quality of life may decline.

In this section, I reviewed socially constructed medical knowledge of autism—medicalization of autism, geneticization of autism, physical reductionism and mind-body dualism and dietary interventions for autism. In the next section, I review cultural meanings attributed to autism, which is another aspect of social construction of autism along with medical knowledge of autism and lived experience of autism.

**Cultural Meanings Attributed to Autism**

**Disability or difference.** Researchers, health professionals, parents of autistics, and autistic adults debate over whether autism should be viewed as a disability or as a difference particularly because individuals who were diagnosed with Asperger’s syndrome can be “highly functional”¹ (Clarke & Van Amerom, 2008). The view that autism is a difference is preferred by individuals with the condition because the term ‘difference’ is a “more neutral, value-free, and fairer description” (Baron–Cohen, 2000, p. 489). It may be true that autistic individuals have a different cognitive style and a different way of being. Autistic individuals have strengths and deficits that are quantitatively and qualitatively different from those of other individuals without it. But, at the same time, Baron–Cohen argued, the difference can be viewed as disability since the concept of disability is relative to particular environments. He suggested that if a society legally protects a right to access to support and accommodations for special needs only of individuals who have conditions that constitute disabilities, the term disability may need to be retained with Asperger’s syndrome. This is for political, not medical reasons.

¹ The functioning labels, “high-functioning autism” and “low-functioning autism,” have been criticized by autistic individuals (e.g., Sequenzia, 2013) and disability scholars (Davidson, 2008).
Autism as invisible disability. Autism and its many co-existing conditions such as attention deficit/hyperactive disorder, depression (including seasonal affective disorder), anxiety disorder, sleep disorder, fibromyalgia, irritable bowel syndrome, hypoglycemia, food sensitivity and multiple chemical sensitivity (Lawton, 2007), are considered invisible disabilities. Invisible disability is a physical or mental impairment that is not immediately apparent to casual observers (Davis, 2005).

Invisible disabilities are usually concealable and therefore those whose disabilities are invisible will often tend not to disclose their conditions in this society in which being ‘intact’ is interpreted as more compelling (Davis, 2005). In order to receive assistance or accommodations, those with invisible disabilities must reveal the fact of disability and usually detailed information about the disability, which is often intensely personal. Even after proving a diagnosis of the disability a person may face suspicion if a disability is newly labeled diagnosis or there is controversy over diagnostic criteria (Davis, 2005).

Based on the advantages and disadvantages of the disclosure, people with a diagnosis of autism spectrum decide whether to inform others of their diagnosis, and, if so, they decide how to, whom to, and when to inform (Attwood, 2007). The advantages of the disclosure for the individuals with autism spectrum can be that people around them are more likely to understand their abilities and difficulties and provide support to meet their needs. However, a negative reaction from others is possible because of the perceived stigma associated with autism.

Identity politics and neurodiversity movement. Although adverse perception and medical understanding of autism is more common in our society, many individuals on the autism
spectrum do not view themselves as people with disabilities. In fact, many of them have superior abilities in the areas of mathematics, physics, logic, art etc. In those fields, autistic traits, including intense concentration, tendency to focus on details, fascination with systemizing, eccentric ways of thinking, are necessary to be successful (Asperger, 1979; Fitzgerald, 2004, 2005). Notwithstanding, these positive aspects of autism have received little attention from most of the professional literature on autism spectrum, which mainly emphasizes deficits and weakness.

To respond to the popular adverse perception and medical understanding of autism, people diagnosed with autism began to develop their own voices, founding Autism Network International in 1993. This international online/offline community of people on the autism spectrum developed a neurodiversity movement (Jaarsma & Welin, 2012). The founders of the movement rejected the presumption of disability. Its members perceived themselves as a part of a distinct culture, not as a group of people with disabilities. Thus, they resisted sympathy from neutrotypicals whose perception of normality is different from theirs (Bowker & Tuffin, 2002, 2002; Bumiller, 2008). The neurodiversity movement opposes those who advocate for a cure (Ortega, 2009).

**Access to accommodations.** Even though many individuals on the autism spectrum do not view the spectrum as a disability, they may decide to keep a low profile regarding the diagnosis because they do not want to be misunderstood as defective through the disclosure. Unfortunately, those who do not disclose their autism diagnosis or those who are not aware that

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2 In contrast, Autistic Self Advocates Network (ASAN), an organization run by Autistic self-advocates, considers autism as a disability and it “seeks to advance the principles of the disability rights movement with regard to autism” (ASAN, 2015).

3 Although the founders of the movement resisted sympathy from neutrotypicals, it should be noted that autistic adults do not always resist sympathy per se since they are often interested in supports (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2012)
they are on the autism spectrum may have only limited access to accommodations; our society does not legally protect a right to access to accommodations for special needs of individuals who do not disclose conditions that constitute disabilities (Attwood, 2008). Environments in which environmental accommodations are already embedded may better enable individuals on the autism spectrum to experience environments without a sense of otherness. Universal design approaches may help designing inclusive places for autistic individuals. Universal design is “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (Center for Universal Design, 1997). Whereas design parameters for wheelchair accessibility and the needs of visual impairment have been well documented in universal design literature, those for physiological, sensory, neurological, mental challenges have not (Froyen, 2008).

Lived Experience of Autism

Lay people with lived illness experience are “becoming more actively involved in producing and consuming knowledge about their own health conditions” and lay knowledge of illness is suggested to “supplement medical knowledge and positively influence health outcomes” (Conrad & Barker, 2010, p. S72-S73). This section reviews literature on lay knowledge of autism from lived experience of autism, lived experience of medical treatment of autism, and lived experience of behavioral treatment of autism. The literature on the lived experience of autism that is reviewed below assures the importance of directly hearing the “voices” of autistic adults, which may allow overcoming the limited view of autism.

Lay knowledge of autism from lived experience of autism. Many individuals on the autism spectrum live with various neurological, physical, and mental conditions in addition to the core symptoms of autism spectrum. While considering that interventions to treat health
conditions associated with autism are appropriate, many proponents of the neurodiversity movement reject the notion of cure for autism (Dubin, 2011). KenG (2011) wrote in an autism self-advocate Internet Web site, “Curing medical conditions which are common among Autistics is totally different from "curing" Autism. Nobody objects to curing such medical conditions, but you need to be explicit about the huge differences between such conditions and autism itself.” KenG wrote this in a response to Dana Marnane of Autism Speaks, an autism advocacy organization that focuses on cure of autism. The Global and Regional Asperger Syndrome Partnership (GRASP), which subscribes to the neurodiversity perspective, stated that the notion of cure of autism is not only “hurtful for those on the spectrum” but also “medically inaccurate.” On the other hand, GRASP acknowledged benefits of treatment for comorbid conditions of the autism spectrum. Allen Markman, a former board member of GRASP, wrote the following:

Anxiety, depression, gastrointestinal problems, and a whole slew of other medical and psychiatric conditions can accompany autism spectrum diagnoses…Children and adults will benefit from treatment of their comorbid conditions, especially if it is understood that they are part of a larger syndrome and not just medical conditions that appear “out of the blue.”

Although autism self-advocacy groups that subscribe to the neurodiversity perspective state that impairing medical conditions that are common among autistics are completely different from autism itself, “the determination of which symptoms constitute difference and which constitute impairment remains vague” (Nadesan, 2005, p. 208). As reviewed above, medical knowledge, including diagnostic criteria, is socially-constructed and definitions of core symptoms of autism spectrum have been changed over time. Most notably, after many individuals on the autism spectrum as well as researchers and medical professionals pointed out
that the sensory sensitivity issue is a core characteristic of autism spectrum disorder, behaviors related to hyper- or hypo-reactivity to sensory input have been officially included in the 5th version of the diagnostic manual (APA, 2013; Lord & Bishop, 2015).

Some autistic individuals are not actively involved in the neurodiversity movement and are more focused on amelioration of comorbid conditions of autism. Listening to their voices as well may be a way of going beyond the dichotomy of cure of autism versus acceptance of autism. Emphasis on amelioration of comorbid conditions of autism as a middle ground between the pro-cure and anti-cure arguments has been envisioned by Donna Williams (n.d.), co-founder of the Autism International Network (ANI), which is one of the first international advocacy organizations run by and for autistic people. Whereas Jim Sinclair, another co-founding member of ANI, became a key figure in the neurodiversity movement with his iconic essay, Don’t Mourn for US, she has stayed one step aside of the neurodiversity movement (Williams, 2010). In her blog, she posted her interview answers for a dissertation on woman and the neurodiversity and autism:

Coming from a position of someone with significant health issues, co-morbid and agnosias, I empathised with families who wanted treatment and so, whilst I equally advocated for recognition of our equality, our right to be ourselves, use our own systems, I never became part of the war between culturalists and cureists. I was criticised for this, sometimes very publicly hated, but I had to be who I am. (Neurodiversity questions section, first answer)

She argues that “there IS a middle ground between the 'culturalists' and the 'cure-seekers' in which both perspectives are recognized and respected”; she describes 'culturalists' as those who

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4 The neurodiversity questions were asked by Kate Boundy, a graduate student working on the dissertation on woman and the neurodiversity.
“tend to see Autism Spectrum Conditions as a shared culture” and “have widely attacked pressure groups which seek to 'cure' or 'eradicate' Autism Spectrum conditions” whereas ‘cure-seekers’ as “those who seek a 'cure' or eradication of Autism from the planet” (Williams, n.d.). Based on her own experience, she believes in the symbiosis:

I'd not be able to cope or relax into my 'cultural differences' had I not also sought and maintained treatment for gut/immune, mood, anxiety and compulsive disorders which have at times been so severe and distressing as to pose very real threats to my health and life.

**Lived experience of medical treatment of autism.** Over-medication, a major problem of medicalization (Conrad, 2007), has been criticized by many autism self-advocates. GRASP (2013) stated that it is “comfortable” with its “misrepresented reputation” as being “anti-pharmaceutical” because its community takes a high percentage of the pharmaceuticals and “has undergone too many horrific experiences of misprescribed pharmaceuticals throughout their lives for [the community] to believe that; just because [Asperger’s syndrome] is now in the DSM, that this suddenly guarantees that what is currently being prescribed is appropriate.” Temple Grandin, one of the best known autism self-advocates, also strongly opposes the current prevalence of the over-medication of autistics, particularly of young autistic children, although she believes in the benefit of careful use of pharmaceutical drugs, such as a low dose of antidepressants which have greatly helped her manage anxiety and panic attacks (Grandin & Panek, 2013).

**Lived experience of behavioral treatment of autism.** In addition to medical treatments, individuals on the autism spectrum receive social skill training and cognitive behavioral therapies, and occupational therapies. However, evidence supporting the efficacy of particular
therapies is limited (Lai & Baron-Cohen, 2015). Furthermore, the challenging responsibility of receiving these therapies is upon the individuals.

The public health response to autism, which is supposed to be directed toward prevention of illnesses at the population level by definition, is currently limited to recommending behaviorally-based early screening and intervention for autism because a definitive and generalizable etiology of autism is not established (Newschaffer & Curran, 2003). The reason of its emphasis on early diagnosis of autism spectrum lies in claims that “behaviorally-based interventions started early in life can curtail problematic behavior and foster communication and social skill growth” (p. 394).

Behavioral therapy has been criticized by many autistic adults who were subjected to it as children for its coercive and demanding, but “seemingly meaningless,” nature (Nadesan, 2005). The limitation of behavioral therapy may lie in its inability in altering underlying reasons of autistic behaviors, such as lack of eye contact and repetitive body movements.

Lack of eye contact is common among individuals on the autism spectrum (Lawton, 2007). According to Lawton, a naturopath doctor, adults with Asperger’s syndrome explained to her that they “avoid others’ gazes as a way to decrease overstimulation” (p. 17). In *Look me in the eye: My life with Asperger’s*, John Elder Robison (2008) writes he does not look at people in the eye not only because he “really [doesn’t] understand why it is considered normal to stare at someone’s eyeballs” but also because he “find[s] visual input to be distracting” when he speaks (p. 3). Carly Fleischmann (2012), a non-speaking autistic teenager who can fluently communicate by typing with one finger, wrote that she has trouble looking at people’s faces because she takes so many pictures of what she sees and experiences visual sensory overload (p. 365).
Such autobiographical insights from autistic individuals suggest that their autistic behaviors should not be forced or changed through behavioral therapies while the issue of sensory overload and underlying reasons, such as lack of certain nutrients, are not addressed. For example, omega-3 essential fatty acids, which are deficient in autistic individuals, have been found to improve eye contact (Bell et al., 2004; Campbell-McBride, 2010; Lawton, 2007).

While both Temple Grandin and Carly Fleischmann are living role models for numerous autistic individuals who would live up to their full potentials under intensive early behavioral interventions, many other autistic individuals and their families cannot afford long hours of behavioral therapies. While therapies are covered for children under age 21 by the Individuals with Disabilities Education Act (IDEA), autistic adults do not usually have this benefit and must pay for therapies on their own.

Food Environment, Foodways and Autism

Environment and health. The relationship between environment and health has been well documented. Environmental psychologists have extensively researched the health effects of environmental stressors, such as noise, crowding, inappropriate lighting, lack of control over privacy, and wayfinding (Evans, 1980; Evans & Cohen, 1987; Proshansky, Ittelson, & Rivlin, 1970; Zimring, 1981). The restorative effects of the natural environment (S. Kaplan, 1995), which have been long believed, are receiving ever-increasing attention from scholars. Their studies show that the natural environment restores psychological health from stress, facilitates physical activity, and helps, through sunlight, synthesis of vitamin D (Faber Taylor & Kuo, 2011; McCurdy, Winterbottom, Mehta, & Roberts, 2010), which is found to be associated with numerous health issues (Holick, 2004).
Researchers from public health, a field of study that focuses on prevention of disease at the population level, primarily focus on the environmental factors that engender obesity-related unhealthy behaviors (Adler & Stewart, 2009). Physical and social environments have been linked to resources and choices available to individuals. The built environment affects walking and other forms of physical activity. Neighborhood characteristics also matter for health (Cubbin, Egerter, Braveman, & Pedregon, 2008). Neighborhood physical environments shape physical activity through various venues. A neighborhood with more litter, vandalism and graffiti is perceived as dangerous for walking or exercising (Heinrich et al., 2007). Residents of unsafe neighborhoods show higher body mass indices (BMIs) (Adler & Stewart, 2009; Doyle, Kelly-Schwartz, Schlossberg, & Stockard, 2006). A neighborhood’s food environment influences dietary behavior, which translates to weight control. Areas where the availability and affordability of foods that may benefit health are restricted are defined as food deserts (Cummins, 2014). An abundance of fast food outlets is linked to obesity. Proximity to supermarkets with fresh fruits and vegetables has been associated with less obesity whereas proximity to small convenience stores with virtually no fresh produce has been associated with more obesity (Cubbin et al., 2008; Morland, Diez Roux, & Wing, 2006).

Emphasis on the role of environments in health is a key aspect of health-promotive environments. Health-promotive environments refer to “environmental resources and interventions that promote enhanced well-being among occupants of an area” (Stokols, 1992, p. 6). Stokols developed the concept, pointing out the limitation of health promotion programs that did not pay attention to the role of the physical environments in individuals’ behavioral changes: “[the majority of health promotion programs implemented in corporate and community settings] have been designed to modify individuals’ health habits and life-styles … rather than to provide
health-promotive environments (p. 6).” In an analysis of potentials and pitfalls of work-site health promotion, (Conrad, 1987) also previously criticized that health promotion programs have been focusing on changing individuals’ behaviors while neglecting the environment.

The concept of health promotion is useful in understanding environmental settings and sociocultural contexts for health and healthy practices of people on the autism spectrum. It frames health as optimal states of relative well-being, not simply absence of disease. This way of understanding of health is in line with the salutogenic approach to health (Antonovsky, 1979), which contrasts with the biomedical or pathogenic approach to health by conceptualizing an etiology of health rather than an etiology of disease. The concept of health-promotive environment can challenge society’s limited approach to autism, which has targeted individuals, focusing on pharmaceutical treatments, behaviorally-based interventions, and search for “susceptible” genes. Without pathologizing autism, one can discuss how to promote health of individuals on the autism spectrum. The concept of health promotion leaves a room to consider ways to improve autism’s Dis-ease aspect, which is neither presence of disease nor optimal state of well-being. The Chiropractic term Dis-ease means “lack of ease or harmony within the body” (Fleischer, 2010)

Although design and planning decisions for general health-promotion or those for reducing other conditions, such as obesity, can be modified for autism, the biological, sociocultural contexts of the spectrum need to be considered. There is not much awareness about what to do with unique characteristics of the autistic population in terms of how to design and plan health-promotive environment for them. Hearing voices from individuals on the spectrum is critical in understanding such environment for them.
Foodways and the food environment of autistic individuals. The food environment and foodways of adults on the autism spectrum have rarely been explored together in scholarly research. Understanding of the ‘place’ of foodways has been limited (Brown, 2008), particularly in the context of autism. Most studies on foodways of individuals on the spectrum have focused on autistic children’s “picky eating” behavior in relation to their sensitivities to taste, texture, or smell of food (Cermak, Curtin, & Bandini, 2010; Ledford & Gast, 2006; Schreck, Williams, & Smith, 2004). A few human geography studies dealt with how autistic adults negotiate university spaces, such as student pubs (Madriaga, 2010) and public eating places (Davidson, 2010). Inaccessible eating places due to sensory overload were raised as a reason for social isolation, which, in turn, resulted in depression, a common mental health issue among individuals on the spectrum (Madriaga, 2010). Research on grocery shopping places that autistic adults find problematic or supportive is even more limited although being able to do grocery shopping is an important independent living skill and autistic adults often find the activity challenging. Personal accounts of autistic individuals reveal that grocery shopping is difficult because of overwhelming environmental stimuli, with the many branded goods competing for a shopper’s attention, of the grocery places: “I was terrified of going into the supermarket, for example; there was too much sound, too many people and vendors offering tasty but unwanted food” (Shore, 2003, p. 31). In an online poll by a non-profit group that provides services for people on the autism spectrum, restaurants and supermarkets were voted as the top two places most respondents would like to see made more accessible (Dimensions, 2012). The literature on foodways and the food environment needs to explore food-related places that are considered important by autistic individuals.
On the other hand, foodways are the ground where identity is communicated (A. R. Kaplan, 1984), and identity issues are linked with self-awareness of autism (Ortega, 2009). Influence of conceptions of autism, such as autism as deficits or difference or both (Kapp et al., 2012), on foodways needs further understanding. Food “indicates who we are, where we came from, and what we want to be” (Belasco, 2002, p. 2). According to Annie Hauck-Lawson (1992), who termed food voice as “the voice of people as food makers and food consumers” (p. 7), food is “a powerful, highly charged, and personalized voice” (p. 6). An autistic person’s food voice regarding a specific diet as a treatment for autism may reveal whether the person embraces autism as either positive or negative identity marker and whether the person considers autism as neurological difference or medical pathology. If the person does not believe in the notion of treating autism but has dietary restrictions for food-related sensory preference or for medical conditions that commonly accompany autism, the person’s experiences with food environments for grocery shopping and dining out as well as food sharing social relationships may still differ from others who do not have such restrictions.

**Research Questions**

In this dissertation study, I explored how autistic adults with different conceptions of autism negotiate and navigate their food environments. The study has the following three areas of inquiry:

1. What are autistic adults’ beliefs on the relationship between diet, autism and health?
   - How are their conceptions of autism related with their responses to a claim that certain diets ‘help with autism’?
2. What are autistic adults’ everyday foodways—beliefs, desires and practices surrounding food consumption, preparation, and production?
   - What do they eat or do not eat, and why?
   - Where and with whom do they eat, and why?
   - Where and how do they do grocery shopping, and why?
   - How and what do they cook, and why?
   - If they produce food, how do they do it and why?

3. How do autistic adults perceive and experience their food environments as supportive or problematic in their everyday food behavior?
   - What challenges do they face as they navigate and use the food environment?
   - What are the characteristics of the physical attributes of food places that are perceived and/or experienced as supportive or problematic?
   - How do their sensory sensitivity issues influence their access to food and food places?
   - What are their strategies to negotiate the barriers they encounter within their everyday food environments?
   - How does food availability influence access to food and food sharing social relations?
Chapter III

RESEARCH DESIGN AND METHODS

The primary purpose of this dissertation research is to explore how adults on the autism spectrum navigate and negotiate their food environments. Three areas of inquiry are the following: 1) What are autistic adults’ beliefs on the relationship between diet, autism and health? 2) What are their everyday foodways—beliefs, desires and practices surrounding food consumption, preparation, and production? and 3) How do they perceive and experience their food environments as supportive or problematic in their everyday food behavior? In this chapter, I describe research design and methods that I used to answer the research questions. After a brief discussion of philosophical worldviews that have influenced the research design, I introduce exploratory research, online research and participatory research that I used for this research. A description of the specific data collection methods, including an online survey and on/offline interviews, follows. Lastly, I outline data analysis.

The Philosophical Worldviews of the Study

A key characteristic of the field of environmental psychology is its problem-focused approach (Steg, Berg, & Groot, 2012). As an environmental psychologist, I hold a view that research has to contribute to solving real-life problems and all available research methods and techniques need to be used to answer the research question. I also believe that research may be influenced by several philosophical worldviews, which are not necessarily mutually exclusive. The pragmatic paradigm seemed to be an appropriate philosophical worldview that would guide this dissertation because “pragmatism opens the door to multiple methods, different worldviews, and different assumptions, as well as different forms of data collection and analysis” (Creswell, 2013, p. 11). This research is also influenced by the transformative worldview, which holds that
research needs to contribute to changing lives of (marginalized) individuals or the world they live in. The major elements of research that draws on transformative worldview are being political, power and justice oriented, collaborative, and change-oriented (Creswell, 2013, p. 6). This research aims to ultimately contribute to making changes in the food environment for adults on the autism spectrum by collaborating with them and lifting up their marginalized voices.

**Exploratory Research**

The purpose of research can be exploratory, descriptive, predictive, or explanatory, while these categories are not mutually exclusive and a study can serve more than one of these purposes (Babbie, 2015). This current study has emphasis on *exploring* foodways and food places of autistic adults. Stebbins (2001) defined social science exploration as following:

Social science exploration is a broad-ranging, purposive, systematic, prearranged undertaking designed to maximize the discovery of generalizations leading to description and understanding of an area of social or psychological life. Such exploration is, depending on the standpoint taken, a distinctive way of conducting science—a scientific process—a special methodological approach (as contrasted with confirmation), and a pervasive personal orientation of the explorer. (p. 3)

The focus of exploratory research is on gaining familiarity with the subject of study that is relatively new (Babbie, 2015). Primary aims of exploratory research are to examine the feasibility of more extensive future research and to test and investigate research methods to be used in future research rather than providing definitive answers to research questions (Babbie, 2015). The number of research participants or sample size of exploratory research is typically small, and findings of exploratory research are neither confirmative nor generalizable. In spite of its limitations, exploratory research is needed when there are few or no studies on the subject
area. Arguing for the significance of exploratory research, Stebbins (2001) listed three conditions where such research is conducted:

In general, exploration is the preferred methodological approach under at least three conditions: when a group, process, activity, or situation has received little or no systematic empirical scrutiny, has been largely examined using prediction and control rather than flexibility and open-mindedness, or has grown to maturity along the continuum […] but has changed so much along the way that it begs to be explored anew.

(p. 9)

This study used an exploratory research approach because there are few studies on foodways and food places of autistic adults that focus on their own perspectives and lived experiences. Although there has been growing interest in adults on the autism spectrum, research on this population is still in a preliminary stage. Autistic persons’ atypical reactions to environmental sensory stimuli, including foods, have been investigated mainly through the lens of medical model of autism, and the focus has been on their sensory ‘dysfunction’ to be ‘fixed.’

Exploratory research may be qualitative or quantitative, although most researchers who conduct exploratory research in the social sciences seem to prefer “mixing the two,” with qualitative data being primary and quantitative data being secondary (Stebbins, 2001). In this research, I also used qualitative data as primary and quantitative data as secondary.

**Quantitative and Qualitative Research**

Quantitative research examines the relationship among variables, collecting numerical data that provides description of characteristics of a set of participants. Qualitative research explores the meaning participants ascribe to a problem or issue, collecting multiple forms of
word data. I collected both qualitative and quantitative data in order to minimize any frustration that might be experienced by autistic individuals while participating in this research.

Questionnaires made solely with close-ended questions may frustrate autistic participants who have atypical cognitive styles, by giving too limited answer options or asking about situations that can be interpreted in too many different ways. For instance, Daisy, a GRASP member who was self-diagnosed with Asperger’s syndrome, wrote on its blog about being frustrated with some of the questions from the Autism-Spectrum Quotient (AQ) test (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001), which has only close-ended questions. Many parts needed to be clarified for her before answering how much the person agreed with statements such as “I would rather go to the theatre than a museum.” She wondered, “What is playing at the theater? Who would I be going with? How much am I paying for the ticket?” On the other hand, questionnaires or interview protocols which use only open-ended questions also may make them wonder too much about how to answer. To use Tony Attwood’s illustration, a child with Asperger’s syndrome might find his mother’s open-ended question, “What did you do at school today?”, too difficult to answer, and even refuse to answer because it is not clear exactly what his mother wants to know and how much detail is expected (2007, p. 116).

To develop a better understanding of how autistic adults negotiate and navigate their food environments, I collected both quantitative data and qualitative data. Based on a preliminary blog analysis and literature review, I have developed survey questions. The qualitative data from the blogs helped me with the development of the interview questions as well. Based on each participant’s survey answers, I modified interview questions for each of them to make the questions more relevant for the participant.
Online Research

This research includes an online research approach as a useful way to lift up marginalized voices of adults on the autism spectrum and improve the validity of the research. *Our Voice* is the title of the Autism Network International (ANI) newsletter first issued in 1992 (Sinclair, 2005). The title of the newsletter reveals how much autistic voices had been ignored and excluded in the thinking and conversation about autism. A main reason that their voices have not been heard may be the fact that “deficits” in communication is one of the key diagnostic criteria of autism. However, many autistics have found their means of communication: the Internet. Text-based communication is generally preferred by individuals with autism over other means of communication and the Internet is an important method of their communication (Davidson, 2008). The impact of the Internet usage on autistics is comparable to that of “the spread of sign language among the deaf” (Singer, 1999, p. 67).

Quality of life of individuals on the autism spectrum has received significantly less attention than “cure” of autism in autism research partly because their voices have been excluded from research on them (Nicolaidis et al., 2013; Robertson, 2009). Through the Internet and text-based communications, individuals on the autism spectrum can participate in research that may contribute to improving their quality of life.

Participatory Research

This study used participatory approaches. Participatory research emphasizes “a ‘bottom-up’ approach with a focus on locally defined priorities and local perspectives” (Cornwall & Jewkes, 1995). ‘Participation’ in participatory research is more than just taking part (Rifkin, 1994, as cited in Cornwall & Jewkes, 1995). Though conventional research also involves ‘participation,’ the extent of participation in most conventional research is limited to the
contractual relation, in which “people are contracted into the projects of researchers to take part in their enquiries or experiments” (Biggs, 1989, as cited in Cornwall & Jewkes, 1995, p. 1669). Biggs’ three other modes of participation that are increasingly ‘deeper’ participations are the following:

- consultative—people are asked for their opinions and consulted by researchers before interventions are made;
- collaborative—researchers and local people work together on projects designed, initiated and managed by researchers;
- collegiate—researchers and local people work together as colleagues with different skills to offer, in a process of mutual learning where local people have control over the process.

The ideal type participatory research involves the collegiate level of participation, though this level is rarely achieved in practice. A model of such ideal participatory research is community-based participatory research (CBPR).

According to Minkler and Wallerstein (2011), community-based participatory research (CBPR) in the field of health is defined by the W. K. Kellogg Foundation’s Community Health Scholars Program (2001, p. 2) as

a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities. (p. 4)

CBPR has been recently suggested as an important approach in studies to enhance the quality of life of adults on the autism spectrum (Robertson, 2010; Nicolaidis, et al., 2013). Communities of
individuals on the autism spectrum exist both globally and regionally (Chamak, 2008; Sinclair, 2009), and are accessible through the internet.

My study is partly influenced by the mission of the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE), a community-based participatory research collaboration with the autistic community. AASPIRE is composed of autistic self-advocates and academics. From the members’ point of view, the existing autism literature had many problematic issues:

A misalignment between researchers’ priorities and those of the autistic community; a lack of inclusion of autistic individuals in the research process; use of demeaning or derogatory language and concepts; threats to study validity derived from miscommunication between researchers and participants; and the use of findings to advance agendas that opposed community values (Nicolaidis et al., 2011, p. 144).

The mission of AASPIRE stemmed from the members’ frustration with the autism literature. Its mission is as follows:

to encourage the inclusion of people on the autism spectrum in matters which directly affect them; to include people on the autism spectrum as equal partners in research about the autism spectrum; to answer research questions that are considered relevant by the autistic community; to use research findings to effect positive change for people on the spectrum.

In the CBPR process of AASPIRE, academic and autistic community members collaborate to decide research topics, “design protocols, develop and adapt instruments and consent materials, recruit participants, collect and analyze data, and disseminate findings” (Nicolaidis, et al., 2011, p. 145).
Although my current study is not CBPR because it is not situated at the collegiate level of participation, which is one of the key elements of CBPR, it adheres to some principles of the CBPR approach. I accomplished the following:

- chose a research topic that is considered relevant by adults on the autism spectrum
- chose data collection methods that would accommodate their preferred ways of communication
- have involved several individuals on the spectrum and the parents of autistic adults in the processes of developing and adapting questionnaires and revising consent materials
- have involved individuals on the spectrum in recruiting participants

A more detailed description of the participatory aspects of my study follows.

**Participatory aspects of this study.** My research topic and research questions grew out of my close discussions with a friend of mine, Drew. They⁵ was very sensitive to light, sound, smell, and taste and was constantly looking for a solution for personal everyday struggles with “what to eat, where to eat, and when to eat.” Drew also had several health issues such as sleep problems and slow digestion. While not having been officially diagnosed with autism spectrum disorder, they has an Autism-Spectrum Quotient (AQ) (Baron-Cohen, 2001) score higher than the general population. They is also “very likely neurodiverse (Aspie)” according to the Aspie Quiz (neurodiverse (Aspie) score = 144 of 200, neurotypical (non-autistic) score = 70 of 200), a

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⁵ Drew is a long time user of singular they. Drew said, “I didn’t like using the gender specific he, she pronouns so I looked up the dictionary more than ten years ago and found that singular they was widely used until the 18th, 19th century. Shakespeare and other famous writers used they, too. I began to use they since then.” That was before singular they became well-known gender-inclusive language. Drew added, “I fought so much with people because they complained that I use they instead of he or she.” Preferred pronouns of all interview participants whose gender is other gender was ‘they/them/their.’ In an effort to respect their preference and follow the APA style guideline that encourages referring participants in the way they prefer, I will refer each of them as they as necessary. I italicize the pronoun in order to avoid any confusion between ‘singular they’ and ‘plural they,’ where the latter is a more common usage and the only accepted usage of ‘they’ by the APA style guideline, by which this dissertation in a field of psychology needs to abide.
popular online self-test quiz that is developed to test how one is likely to be neurodiverse (Ekblad, 2013)

Autism and Drew’s issues with sensory sensitivity, “feeding,” and health issues seemed to be all somewhat connected to each other as we more discussed on these topics. For example, their skipping meals due to lack of access to places to comfortably eat or many other various reasons seemed to be related to sleep disturbance, which is a common health condition among autistic individuals. Drew usually skips breakfast because they gets up late due to poor quality of sleep, and does not have appetite in the morning feeling the undigested food from the previous night. They would just drink a cup of coffee to be alert to go to work. Because of a busy schedule and having no place to comfortably eat lunch, they often skips eating even lunch and “kills hunger” with some vending machine “junk food.” By the time they arrivals home at late night, they is starved and often eats an enormous amount of food and feels bloated if they is lucky enough to have food to eat at home; on “unlucky” days, they has no food to eat at home and all restaurants that serve proper food are closed by the time. Either because they feels too bloated or starved, their quality of sleep is poor again.

Drew also played an important role in revising my survey and interview questions as a “translator” between individuals on the autism spectrum and me. While conducting a pilot interview with them via Skype, an Internet phone service, I clarified interview questions based on their answers and suggestions. Because their important health and diet related issues were well known to me, I could easily tell whether they understood the question correctly or did not fully answer the question. They provided rich, critical feedback and suggestions throughout the interview. The very first suggestion was to conduct an online survey with multiple choices and open-ended questions instead of conducting phone interviews. They explained that writing is a
A better method for communicating because participants can answer when they have time and it is a more anonymous method than others.

A college student who has been diagnosed with Asperger’s syndrome also inspired and helped me with developing this research. I met "Mastermind" (his chosen pseudonym) and his mother at a conference for adults on the autism spectrum. While eating together at their home, eating out and going grocery shopping with me, Mastermind and his mother shared with me their needs and concerns regarding their foodways and health issues. Based on my observations of and conversations with them, I have revised questions for an online survey and interviews. Mastermind also inspired me to conduct face-to-face interviews as well as online interviews. He initially told me that he would prefer having an email interview to having a face-to-face interview, but he later very much enjoyed our improvised, casual walk-along interview style conversations. His mother also encouraged me to talk with him face-to-face as well as exchanging emails because he did not have many chances to socialize and he said he felt comfortable talking with me.

When I was invited to their house for the first time, Mastermind helped me editing the informed consent form and the questions for an online survey and interviews to make sure those materials were written clearly for adults on the autism spectrum. Mastermind’s responses to close-ended questions also confirmed the importance of having open-ended questions where autistic individuals may explain what they really meant when they have chosen certain answers for close-ended questions.

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6 He explained later that he chose “the mastermind” to be his pseudonym because his personality type is INTJ (introverted, intuitive, thinking, judging) according to the Myers–Briggs Type Indicator (MBTI) and the INTJ personality type is known to be the mastermind personality.
When I was invited to his house again for a holiday dinner, Mastermind participated in a
pilot online survey. Although he was initially fine with open-ended questions regarding
foodways (e.g., “What do you like most about eating outside? What do you dislike most about
eating outside? Why?”), when we were revising the survey questions and answered other open-
ended questions (e.g., “What is autism in your own words?”), he asked me if he might skip those
foodways-related open-ended questions. I answered that he might skip any open-ended
questions, but asked why he wanted to skip. He explained that those questions required too much
thinking and made him getting anxious. He talked about his anxiety issue, which is common
among individuals on the spectrum. I showed him alternative multiple-choice questions
regarding foodways, which had been considered too specific and fact-based questions by non-
autistic individuals who previously reviewed my survey questions. He much preferred those
multiple-choice questions. He was even delighted to see many short answer choices that exactly
matched answers he would give. For example, for a question, “Do you like going grocery
shopping?” he said “I hate it!” and found the exactly same words among the choices. He made a
big smile.

In addition, a friend of mine, who is an autism researcher, and her son, who had been
diagnosed with Asperger’s syndrome, provided me with insightful comments and suggestions on
my online survey questions. I had initially asked for her critique on the materials. She soon
suggested she ask her son to look at them to give his take as a person who had been diagnosed
with Asperger’s syndrome. Though he was not an adult at that time, I gladly consented because
he was registering for a college level psychology class for his coming senior year in high school.
Each of them made many specific comments marking them up on the word files where they
could see the entire online survey questions and emailed the files to me. I made many changes
based on their comments. One of her critical comments was “Be very careful with your words. Some of your participants will read things literally and will have difficulty answering the question.” As she anticipated, her son asked me to clarify meanings of some words that might be read literally. She also made several suggestions about how to recruit parents, “the gatekeepers for their autistic children,” for this study. She explained that the parents will be members of autism LISTSERVs and local groups (especially younger members and “newbie” parents of recently diagnosed children). She later edited my then current dissertation proposal and made numerous critical comments on it.

The executive director of an autism self-advocacy organization reviewed my final draft of the online survey questionnaire and the interview questions. The executive director has been diagnosed with Asperger’s syndrome and served as a facilitator for monthly support group meetings of the organization. The person was very familiar with important issues faced by individuals on the autism spectrum because many issues were discussed during the support group meetings. She confirmed that my research topic targets a very important and relevant issue for those on the spectrum. Though the organization did not focus on diets, she told me about her personal belief that foods and physical activities have tremendous effects on the brain and physical health of persons on the spectrum. She agreed that my research on foodways and the food environment of autistic adults may be a way to balance between the medical model and the social model of autism and contribute to their better quality of life. She approved of all of the questions on the online survey and interview questions. When I asked about how to ask about participants’ income, she suggested giving an option of “Do not wish to say” even when participants will be informed that all demographic information questions may be skipped. She also suggested having other options, including “Supported by family” and “On public
assistance.” She was excited about my research and later helped me distributing recruitment flyers to individuals on the spectrum.

**Data Collection**

My goal was to recruit a wide range of participants who could inform me how adults on the autism spectrum experience their food environments so that the findings of this study may deepen our understanding of an autism-friendly food environment. I focused on recruiting adults on the autism spectrum because they know best how they experience. Inclusion criteria for participation were the following:

- Being able to communicate in written or spoken English
- Being adults who consider themselves to be on the autism spectrum: Either having a formal diagnosis or scoring 14 or higher on the Ritvo Autism and Asperger Diagnostic Scale -14 (RAADS-14) (Eriksson, Andersen, & Bejerot, 2013)

Adults who consider themselves to be on the autism spectrum included both those with a formal autism diagnosis and those with a self-diagnosis. The reason that I recruited those with a self-diagnosis as well was because many autistic adults do not have official diagnoses (Brugha et al., 2011; Lai & Baron-Cohen, 2015). In addition to adults who consider themselves to be on the spectrum, I also recruited some parents of autistic adults for a supplementary online survey and for interviews in order to understand how autistic adults who had difficulty directly participating in this research experience their food environments. Having some autistic participants without a formal diagnosis and parent participants in addition to primary participants with a formal autism

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7 Twenty seven out of the 29 autistic participants were US residents because I recruited participants through US-based autism-related organizations. One diagnosed survey participant was Canadian and one self-diagnosed survey participant was Korean. Soon after I began to recruit other English speakers, the online survey system for this study, Opinio, was closed because of my school’s budget cut.

8 The RAADS-14 will be introduced in detail in the measure section.
diagnosis seemed to be helpful in understanding experiences of autistic adults in a study on healthcare experiences of adults on the autism spectrum (Nicolaidis et al, 2015).

In this exploratory research, I used convenience sampling, which is a type of non-probability sampling method that involves participants who are relatively easy to access and those who select themselves to participate as volunteers. Convenience sampling is “useful for exploratory research, to get a feel for ‘what’s going on out there’…” (Bernard, 2012). Convenience sampling is also commonly used to recruit hard-to-reach populations. Given that the number of autistic adults is much smaller than that of the general population and autistic adults have difficulty in communication, autistic adults are a hard-to-reach population.

On the other hand, I tried to recruit participants with various conceptions of autism and experiences with autism by recruiting participants through autism-related organizations that focus on different subgroups of the autism community and have various understandings of autism that are revealed in their mission statements.

The data collection consisted of two phases: an online survey and online/offline one-on-one interview. Study procedures have been reviewed and approved by the City University of New York Institutional Review Board (IRB).

**Phase 1: Online survey.**

**Recruitment.** I invited adults on the autism spectrum and parents of autistic adults to participate in this research through in-person invitations (see Appendix A), e-mails, and Web-site postings (see Appendix B). During in-person recruitment, potential participants were approached

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9 While self-section bias is problematic in research that intends to make statistical generalization, this current study does not intend to make such generalization.

10 I invited a few non-speaking autistic bloggers to this study but they did not participate. I could have reminded them of my research again but I did not, because there are only small number of publicly known non-speaking, but communicating, autistic individuals, which may result in difficulty in completely disguising their identities when they participate.
in events or meetings organized by local autism advocacy organizations in the New York metropolitan area for adults with Asperger's syndrome or similar autism spectrum profiles (e.g., Global and Regional Asperger’s Syndrome Partnership (GRASP), Asperger’s Syndrome and High Functioning Autism (AHA)). During online recruitment, several autism organizations, including GRASP, AHA, Autism Speaks and autismNOW distributed the participation request. Members of AHA received an invitation via weekly e-Newsletters from the organization for a month. GRASP’s Web page about research and Facebook page, Autism Speaks’s web page about research and AutismNOW’s blog page posted the participation request. Members of some online autism support groups received a forwarded email invitation for the research from the online support group. Lastly, bloggers whose blogs about their lived experiences of autism or who blogs about their conceptions of autism were invited to participate. They were also asked to share the participation request with individuals who might be interested in the research if the bloggers have many visitors and to consider giving me permission to quote their blog posts under a condition that I strictly follow their copyright rules. I sent emails or left messages to bloggers following the blogger’s guideline on how to contact them. Most blogs have a section called, 'Contact me', where a visitor may obtain the blogger's email address or click a link named 'Send an email' or 'Leave a message'.

Participants were informed in the survey consent form (see Appendix C) that they will be entered into a raffle to win one of twenty $25 e-Gift Cards and that if they participate in both survey and interview, their chances of winning will be doubled. The raffle was drawn as soon as all data were collected.

**Survey settings.** Participants were asked to complete a survey for this research through an online survey system, Opinio. The survey participants remain anonymous in default. Participants
who were willing to be contacted for an interview were asked to provide their email addresses; the interview constituted the second phase of this research. If the online survey participant chose to participate in the interview as well, the data from the survey were linked to the data from the interview and were no longer be anonymous. Online survey participants completed an Internet-based informed consent form for the online survey. The consent form includes the research participant information sheet and "I agree" and "I do not agree" buttons for participants to click their choice of whether or not they consent to participate in my research.

I chose to use Opinio mainly for its features that can help reducing potential minimal psychological risks and risks related to privacy and confidentiality. While many individuals on the autism spectrum are proud to be autistic, some would not feel comfortable with potential, unexpected disclosure of their diagnosis. Opinio is password-protected and uses Secure Sockets Layer (SSL) encryption to make sure survey answers not to be seen by any third parties. The survey system also has a “save and continue later” feature. This feature is important because the survey takes approximately 20-30 minutes to complete, and some participants might want to take breaks. When a participant clicks a “Save and continue later” button instead of “Next”, the participant is asked to type an email address and click "Send the link" to save answers and continue later. A link was emailed to the participant that will enable the person to return to survey. The email address for Save & Continue Later was not recorded so the survey is anonymous. Another reason that I used Opinio is that it has a skip logic feature that enabled me to ask only relevant questions based on the earlier replies.

**Measures.** I conducted the online survey to ask about autism spectrum diagnosis history, Ritvo Autism and Asperger Diagnostic Scale -14 (RAADS-14) (Eriksson, Andersen, & Bejerot,
2013), conceptions of autism, quality of life, foodways, and demographic information (For more detailed questions and answer choices, see Appendix D).

*Autism spectrum diagnosis history.* The survey began with a question that asks if participants consider themselves to be on the autism spectrum. Although seeing questions about diagnoses from the beginning might not be very pleasant to some participants, the diagnoses-related questions needed to be placed in the current position because of the skip logic. Questions that were irrelevant to certain participants were automatically skipped based on their earlier replies. Those who answer that they consider themselves to be on the autism spectrum were asked if they were formally diagnosed. Those who answered that they had been formally diagnosed were asked to report their specific autism spectrum diagnosis histories, including their ages at diagnoses. Those who consider themselves to be on the spectrum without being formally diagnosed were asked to answer why they consider themselves to be autistic. This series of questions is essential in this research because my preliminary analysis of blogs of autistic adults implied possible connections between individuals’ specific autism diagnostic histories and conceptions of autism. Conceptions of autism (Kapp et al., 2012) is a key area in this research because they may be related to participants’ beliefs on the relationship between diet, autism and health. Finally, participants were asked if they are the parents of an individual on the spectrum. For the parents of an individual on the spectrum, the above series of questions were asked about their children as well.

*Ritvo Autism and Asperger Diagnostic Scale -14 (RAADS-14).* The RAADS-14 (Eriksson et al., 2013) was used to verify whether each participant is likely to be autistic or not. The RAADS-14 is a short version of the Ritvo Autism and Asperger Diagnostic Scale-Revised (RAADS-R) (Ritvo et al., 2011). The RAADS-14 is a tailored scale to help clinicians to identify
psychiatric patients who may be on the autism spectrum. For my research, the scale was recommended by an autism researcher who is an active autism self-advocate. He considers the RAADS-R to be less judgmental than other self-rating instruments which measure the degree to which adults have autistic traits, including Autism Spectrum Quotient (AQ) (Baron-Cohen, 2001). I decided to use the RAADS-14 to reflect the suggestion of this autistic person. This decision is in line with the mission of AASPIRE: “to include people on the autism spectrum as equal partners in research about the autism spectrum.” In case participants find the RAADS-14 problematic or limited, I asked an open-ended question where they could freely express their thoughts about the scale.

Conceptions of autism. Based on the literature regarding diverse conceptions of autism noted in the table below, along with blog posts written by individuals on the autism spectrum or their parents, I designed 15 statements. Each of the statements briefly summarizes each conception of autism that was frequently mentioned in the literature. Some authors of the references reviewed different conceptions of autism and some supported particular conceptions of autism. The blog posts were found through an autism blog directory, Autism Blogs Directory.

Table 1. Fifteen statements on conceptions of autism based on references

<table>
<thead>
<tr>
<th>Statements</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism is a way of being</td>
<td>Ortega, 2009</td>
</tr>
<tr>
<td>Autism is a disorder</td>
<td>APA, 2013; Clarke &amp; Van Amerom, 2008</td>
</tr>
<tr>
<td>Autism is a part of an individual’s</td>
<td>Brownlow &amp; O’Dell, 2006</td>
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<tr>
<td>identity</td>
<td></td>
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<tr>
<td>Autism needs to be cured</td>
<td>Chauhan, Chauhan, &amp; Brown, 2009; Harmon, 2004; Herbert, 2012; Ortega, 2009</td>
</tr>
<tr>
<td>Autism needs to be celebrated</td>
<td>Jaarsma &amp; Welin, 2012; Ortega, 2009</td>
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<td>------------------------------</td>
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<tr>
<td>Autism needs to be treated</td>
<td>Nadesa, 2005</td>
</tr>
<tr>
<td>Autism is a gift</td>
<td>Lyons &amp; Fitzgerald, 2005</td>
</tr>
<tr>
<td>Autism is a disability</td>
<td>Baron–Cohen, 2000; Bumiller, 2008</td>
</tr>
<tr>
<td>Autism is a natural human variation</td>
<td>Jaarsma &amp; Welin, 2012</td>
</tr>
<tr>
<td>Autism is a genetic condition</td>
<td>Herbert, 2012; Nadesan, 2005</td>
</tr>
<tr>
<td>Environmental pollution causes autism</td>
<td>Nadesan, 2005; Volk et al., 2014</td>
</tr>
<tr>
<td>Autism is a brain condition</td>
<td>Nadesan, 2005; Ortega, 2009</td>
</tr>
<tr>
<td>Autism is a whole body condition</td>
<td>Campbell-McBride, 2010; Herbert, 2012; Herbert &amp; Weintraub, 2013</td>
</tr>
<tr>
<td>Autism is hardwired</td>
<td>Ortega, 2009</td>
</tr>
<tr>
<td>Autism is a biomedical condition</td>
<td>Campbell-McBride, 2010; Herbert &amp; Weintraub, 2013; Nadesan, 2005</td>
</tr>
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</table>

The first set of seven statements were the following: (1) ‘Autism is a way of being,’ (2) ‘Autism is a disorder,’ (3) ‘Autism is a part of an individual’s identity,’ (4) ‘Autism needs to be cured,’ (5) ‘Autism needs to be celebrated,’ (6) ‘Autism needs to be treated,’ and (7) ‘Autism is a gift.’ Six response alternatives for the seven statements were ‘Strongly agree,' ‘Agree,” ‘Neither agree nor disagree,' ‘Disagree,’ ‘Strongly disagree,’ and ‘I don’t know.’ The second set of eight statements were the following: (1) ‘Autism is a disability,’ (2) ‘Autism is a natural human variation,’ (3) ‘Autism is Genetic,’ (4) ‘Environmental pollution causes autism,’ (5) ‘Autism is a brain condition,’ (6) ‘Autism is a whole body condition,’ (7) ‘Autism is hardwired,’ and (8)
‘Autism is a biomedical condition.’ Six response alternatives for the eight statements were ‘Not at all,’ ‘A little,’ ‘Somewhat,’ ‘Mostly,’ ‘Completely,’ ‘I don’t know.’

In addition to the questionnaire with the 15 statements, there were two open-ended questions in the section for conceptions of autism. A question that asks what autism is in their own words gave a chance for the participants to freely express their understandings of autism. This open-ended question would relieve any potential frustrations experienced by those who find questions with multiple choices limited or oversimplified. The other question asked what they think about an idea that certain diets “help with autism.” Their answers to that question provided me with insights that may further explain their choices in the scale as well as their opinions on the relationship between diets, autism and health.

Quality of life. Items for quality of life measure are eight domains of quality of life suggested by Schalock (2004) (i.e., physical well-being, emotional well-being, interpersonal relations, social inclusion, personal growth, material well-being, self-determination, individual rights). Using a five-point Likert scale, I asked participants to indicate how satisfied they are with each of the eight aspects of quality of life and how important each of the aspects is for them. Participants who have adult children answered how satisfied they think their children are with each of the aspects and how important for their children they think each aspect is.

Foodways. I used Counihan’s (2008) definition of foodways in this study. According to her, foodways are the beliefs and practices involved in eating food, going grocery shopping, growing food, and cooking. Participants were reminded of the definition of foodways before being asked about specific aspects of their foodways. There were close-ended questions and

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11 Material well-being is replaced by economic well-being in my research because a person who reviewed my questions misunderstood it as marital well-being.

12 It is important to note that the parents and children will not always think the same way or even report the same way. I will not substitute what a parent thinks for what the adult child thinks.
open-ended questions related to foodways. Most of the questions were multiple-choice questions where participants may select all that apply and a choice of ‘other’ where they could be more specific. The section on foodways started with questions that asked about non-preferred foods and the reasons. Then, participants were asked if they have ever been on any restricted diet. Those who have been on any restricted diet were asked to select challenges in maintaining the diet, such as ‘Hassles,’ ‘Time consuming,’ ‘Socially isolating,’ ‘Expensive,’ ‘Difficulty in finding places to eat out,’ and ‘No improvement in health.’ A series of questions regarding grocery shopping started with a question on how much they like or dislike going grocery shopping. Questions on whether participants go grocery shopping and, if so, how often they go grocery shopping in various kinds of grocery places, including online groceries, followed. The section on grocery shopping ended with questions on aspects of grocery stores that make it hard for them to go grocery shopping (i.e., ‘Smell,’ ‘Noise,’ ‘Lighting,’ ‘Crowding,’ ‘Store layout,’ ‘Location,’ ‘Price,’ ‘Variety of food’) and strategies they use to cope with sensory challenges that they face while grocery shopping (i.e., ‘Wearing sunglasses,’ ‘Wearing a hat,’ ‘Wearing ear plugs or earphones,’ ‘Wearing a mask,’ ‘Shopping at odd hours’ or in the middle of night’). A section on eating out asked a similar series of questions to the ones in the section on grocery shopping. New questions in the section on eating out were questions on whether participants usually eat with others when they eat out and some challenges when eating out with others. The last two sections of questions related to foodways were on growing food and cooking. Given that not many individuals grow their own food even at least in part, I did not ask detailed questions regarding growing food in the survey. Those who indicated that they grew food at least in part and participated in the interview as well were asked about that experience in detail later in the interview. Regarding cooking, participants were asked if they usually prepare, assemble or cook
a meal on their own and what are some challenges when preparing, assembling or cooking. The reason why I include the terms ‘preparing’ and ‘assembling’ in those questions is because the term ‘cooking’ may mean different kinds and levels of activities and some individuals on the spectrum might interpret the term ‘cooking’ too literally. Those who answered that they do not prepare, assemble or cook were asked what the reasons are.

Demographic information. Participants completed a series of items adapted from the United States Census to report gender, age, ethnicity, marital status, employment status, highest level of education, living area (i.e., urban area, suburban are, small town and rural area), living arrangement, and income. A short series of questions about blogging habits were added to the section on demographic information.

The last question of the survey asked participants to provide their email addresses if they are willing to be contacted for an interview, which constitutes the second phase of this research.

Phase 2: Online/offline one-on-one interview. I have conducted 11 interviews (see Appendix E) to understand how certain environmental settings and situations are considered problematic or supportive in relation to everyday foodways of adults on the autism spectrum—the beliefs and practices involved in eating food, going grocery shopping, cooking and growing food.

Procedures. Survey participants who provided me with their email addresses at the end of the survey to be contacted for an interview received an email from me. The email appreciated their participation and gave a link for another Opinio survey page with an informed consent form for the interview. Participants chose to have an online or offline interview. Three types of online interviews were available in this study for participants’ convenience. Participants were free to choose from an e-mail interview, Instant Messaging, or Internet phone interview. At the end of
the consent form, they were asked to give the email addresses they provided at the end of the Phase 1 survey so that I could tailor interview questions according to the survey answers of each participant. Once the participants completed the consent form, I emailed them to set up an interview or emailed interview questions.

In-person interviews were recorded with my digital voice recorder for accuracy of transcribed interview contents. An interview with a participant who felt uncomfortable about having his voice recorded was informed that I would be the only person who will have access to the recording. The person gave me permission to record the interview with a condition that I delete the interview right after I transcribe the interview. I followed the instruction. When recording was not appropriate, I made brief notes during the interview and more detailed notes right after the interview.

The inability of email and Instant Messaging to deliver visual and auditory messages has been typically counted as a limitation in valid interpretation of the conversation (Committee for Protection of Human Subjects, 2014). However, such inability can provide a more equal ground for autistic interviewee and non-autistic (or neurotypical) interviewer to discuss topics relevant to the autistic interviewee, who may have atypical communication styles. Co-directors of the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE), which holds their meetings with text-based Internet chat, explained that “the Internet can equalize communication for autistic adults who may experience challenges interpreting body language, who cannot process auditory language in real time, or who require longer time in conversations” (Nicolaidis et al, 2011, p. 5).

Interview procedures differed by the types of interviews. Although the online and offline questions were the same in order to give a more equal ground for autistic interviewees who feel
more comfortable with online interview and those with offline interview, I had more natural conversations with the interviewee during in-person interviews and an instant messaging interview than during the first round of email interviews, by not necessarily following a list of semi-structured interview questions. For email interviews, participants received an email with interview questions in email text. They were asked to answer interview questions via email. They were informed that they may send their answers once the interview has been completed or send over several occasions and that there will be follow-up email exchanges. They all welcomed follow-up questions. An interview via instant messaging was carried out via Google's chat network. The instant messaging interview participant was informed that the interview will be paused and resumed at any time the participant wants. After two hours passed, I suggested taking a break or resume the interview later, but the participant said the person would be fine with a few more questions. Right after the Instant messaging interview, I copied and pasted the interview into my password-protected computer.

**Interview questions.** Interview questions focused on how certain environmental settings and situations that are considered problematic or supportive in relation to practices involved in eating food, going grocery shopping, growing food, and cooking. Interview questions were tailored for each of the interviewees based on their survey answers. Before beginning to specifically ask about those, I asked two, more personal questions. The first question will be about participants’ journeys until their (or their children’s if the participants are the parents of adults on the spectrum) current autism spectrum diagnoses were, either formally or informally, made. The probing questions were about what their lives were like until the diagnosis, why a diagnosis was sought and how they felt when diagnosed. Except for that first question, all interview questions were solely about autistic adults. The second question asked about health-
related quality of life in terms of their health concerns, ways to manage health, and challenges in managing health.

Then, I asked questions about aspects of favorite places for eating out and challenges in getting there or being there, aspects about least favorite places for eating out, places where they frequently eat out, and their strategies to cope with sensory challenges while eating out, including questions about how they came up with the strategies and if they have any concerns about using the strategies. Their answers about aspects of their favorite eating out places gave insights on environmental settings and situations that are supportive in relation to eating out. Another reason to ask the question about their favorite eating out places is to minimize any psychological risk that might be caused by being asked about negative aspects of their foodways and food environments. By being asked about their least favorite eating out places right after answering about their favorite eating out places, participants could more easily report strong contrasts between those two different quality levels. Poor physical aspects of environmental settings are often overlooked until their qualities become salient. Then, questions about places where they frequently eat out were asked. Those places were not necessarily their favorite places. Regarding grocery shopping places, similar questions were asked.

There were two questions that asked about critical incidents (Flanagan, 1954) experienced by the participant while they were eating out and shopping groceries, respectively. Regarding eating out, I will ask, “Try to remember a recent time when you were very annoyed by some aspects of eating out. How did some of those aspects make it hard for you to comfortably eat there?” Those questions on the critical incidents are based on the critical incident technique (CIT). Developed by John Flanagan, CIT is a well-established qualitative research approach to collect and analyze data about human activities that are significant to the individuals
involved (Hughes, Williamson, & Lloyd, 2007). CIT is described as “a set of procedures for collecting direct observations of human behavior in such a way as to facilitate their potential usefulness in solving practical problems and developing broad psychological principles” (Flanagan, 1954, p. 327). Flanagan explains, “an incident is critical if it makes a ‘significant’ contribution, either positively or negatively, to the general aim of the activity” (p. 338). Being very annoyed by some aspects of a grocery store is a critical incident if the annoyed person cannot successfully complete the grocery shopping activity because of such an incident.

Regarding their food habits, participants were asked about their experiences with being on certain diets. To those who indicated in the survey that they had been on certain diets, I asked questions about what motivated the diets, how they started the diets, what has been challenging maintaining the diets, and what they have successfully done in maintaining the diets. Those who answered that they had never been on any restricted diets were asked what the reasons are. Questions regarding growing food were identical to the ones about food habits except the fact that they are about growing food. The last series of questions in the interview were about cooking. Participants were asked about how they define cooking, what they typically cook and why, how often they cook, how many hours they usually spend cooking per week. They were also asked to tell in more detail about challenges in cooking and strategies they use to cope with the challenges.

**Confidentiality.** In order to reduce the potential psychological risks, participants were allowed to skip any questions that they do not wish to answer and they can quit the survey at any time. For the potential risks related with privacy and confidentiality due to security issues of online interview systems, I used systems that have advanced encryption features. I listened to interviews twice, took notes each time, and transcribe only selected statements. And I kept the
data stored until I have completed the research and then destroyed the originals. In case a participant allows me to record but wants me to delete immediately after I transcribe, I followed the participant’s preference.

In order to make sure that only can I identify the responses of individual participants, I assigned pseudonyms to the participants. I used the pseudonyms as the file names of digitalized recording files and the transcribed interviews and kept a separate document that links the pseudonyms to participants’ identifying information locked in a separate location. I did not assign pseudonyms to participants who specified that they would like me to use their real names. For those who chose their own pseudonyms, I used their chosen pseudonyms.

**Data Analysis**

I analyzed data from 32 survey responses and 11 interviews.

**Identification of major themes and sub-themes.**

I employed an inductive thematic analysis (Braun & Clarke, 2006) for written answers in the survey (i.e., answers to open-ended questions and answers to the ‘other’ option in multiple choice questions) and interview answers (i.e., answers from email interviews and Instant message interviews, and transcripts from in-person interviews). An inductive thematic analysis is a qualitative method, which uses a data-driven approach. In a sense that an inductive thematic analysis identifies themes that are derived from data themselves, this form of thematic analysis is similar to a grounded theory approach (Braun & Clarke, 2006). I used an inductive approach to search for keywords, themes, or ideas that emerge from the data rather than imposing theoretical categories on the data. I identified themes at semantic level. A thematic analysis at semantic level typically focuses on the explicit or surface meanings of the data (Braun & Clarke, 2006). To note themes in the data, I also used Owen's (1984) three criteria of a theme: recurrence,
repetition and forcefulness. Recurrence refers to at least two parts of a data set having the same thread of meaning, which may vary by terms of wording. The second criterion, repetition, is an extension of the first criterion, repetition. Repetition refers to explicit recurrence of the same or relatively the same key words, phrases, and sentences. Criterion three, forcefulness, refers to vocal or written expressions that strongly stress certain ideas (i.e., vocal inflection of tempo, volume and pitch in the oral reports; the underlying, capitalizing, or italicizing of words and phrases in the written reports). Researchers typically require three or more parts of a data set reporting the same idea to be considered a theme in samples more than 20 (Webb & Wang, 2013). I checked how frequently expressions that have the similar meaning were reported. When the same idea was noticed in three or more survey answers or interview answers, I considered the thread of meaning a theme for its recurrence. I considered an idea, mentioned in virtually all sources a main theme. I recognized an idea that is strongly stressed a theme for its forcefulness.

Quantitative analysis. Once I identified major themes and sub-themes based on the qualitative data, I analyzed quantitative data. The demographic characteristics of the participants were compared to both those of the general population and the general autism population. I exported the collected survey answers to Excel from the online survey system, Opinio.
CHAPTER IV
INTRODUCTION OF PARTICIPANTS

In this chapter, I will introduce my research participants. Thirty-two out of 37 participants completed the online survey, and 11 out of the 32 participated in interviews as well. Out of the 32 participants who completed the survey, 29 considered themselves to be on the autism spectrum. The participants who considered themselves to be on the spectrum will be referred as *autistic participants* in this study. Twenty-three of them have been officially diagnosed with an autism spectrum condition. Six out of the 29 autistic participants considered themselves to be on the autism spectrum without an official autism diagnosis. To differentiate those with a formal diagnosis from those without, I will call the former *diagnosed participants* and the latter *self-diagnosed participants*. Three participants who did not consider themselves to be on the spectrum were *parent participants* whose children have been officially diagnosed. Their children will be referred as *diagnosed adult children*. There were five incomplete responses from diagnosed participants; their completed response portions will be mentioned as necessary in a few occasions in the section on autism diagnoses. There was one case where both an autistic participant and the person’s parent participated. For that case, I will report survey responses from the autistic participant instead of the parent’s if the response is about the autistic person, except when I compare their responses. For this reason, only two, instead of three, cases will be reported as cases of diagnosed adult children in descriptive statistics of *autistic adults*. *Autistic adults* in this study include diagnosed participants, self-diagnosed participants and diagnosed adult children.
Characteristics of Online Survey Participants

In this section, I first introduce autistic participants’ reasons to consider themselves to be on the autism spectrum. Next, I report the autistic adults’ specific autism diagnoses. Then, I report their Ritvo Autism and Asperger Diagnostic Scale-14 (RAADS-14) (Eriksson, at al., 2013) scores that indicate if one may be on the autism spectrum. I close this section with participants’ demographic information.

Reasons to consider oneself to be on the autism spectrum. In an open-ended question, participants who were officially diagnosed with an autism condition were asked why they consider themselves to be on the autism spectrum other than because they have been diagnosed, and self-diagnosed participants were asked why they consider themselves to be on the spectrum although they were not officially diagnosed. Notable reasons from diagnosed participants were “because I am,” self-stimulatory behaviors (or stims in short), sensory sensitivities and difficulty in communication. Several participants mentioned that they were basically self-diagnosed before receiving an official autism diagnosis. Some self-diagnosed participants answered that they first took online quizzes that test how one is likely to be autistic, or heard from others about the possibility, and later became convinced that they are on the spectrum after reading more about autism. One of self-diagnosed participants’ readings was DSM-5. Some other self-diagnosed participants did not specify the reasons in detail.

Because I am. A short remark, “Because I am” was offered as a complete answer by three diagnosed participants, one of whom did not complete the survey. A diagnosed participant provided a more detailed answer that might be in line with “Because I am”:

13 Responses from those who did not complete the survey but answered at least up to this question (5) are included in the analysis of the reasons to consider oneself to be on the autism spectrum.
My pathological identification by a professional is actually the LEAST important reason for me to believe that I am Autistic. The fact that I move, feel and think autistically at every waking and non-waking moment is what reminds me that I'm Autistic. Their answers imply that they consider autism as a part of their identities, which is a statement that most autistic participants agreed with.

Other participants answered specifically how they move (e.g., self-stimulatory activity, or stim), feel (e.g., sensory sensitivity), think and communicate (e.g., non-verbal) “autistically,” to use their word. For example, one participant wrote:

The diagnosis I received resonates with me. Ever since I was a young child, others (and myself) have been puzzled by my sensitivity to touch, my ritualistic forms of movement, and my abnormalities in cognition and speech. I have a difficult time regulating myself, psychologically and physically. As an adult, my most troubling symptom is perhaps my executive function issues, as this has impacted my progress toward my Bachelor’s degree and made it difficult to maintain employment.

**Self-stimulatory behaviors.** Self-stimulatory behaviors, or simply stims, was often first mentioned as a part of the answer by participants who were diagnosed with an autism condition as a child or an adolescent (e.g., “I have lots of stims and trouble with eye contact and social situations, noise, overwhelmed, prefer to be alone I have OCD and tourettes as well I also have perfect pitch,” “I share many similarities with other autistic adults. I engage in self stimulatory activity, I have special interests, I conceive of ideas far differently than my nt peers”). A participant who was diagnosed with an autism condition as an adult but received special education as a child, answered that she stims a lot, has difficulties interpreting non-factual info,
social interaction, and works to avoid meltdowns. While many diagnosed participants also mentioned their self-stimulatory behaviors as one of the reasons they consider themselves to be on the spectrum, only one self-diagnosed participant included having self-stimulatory behaviors as a reason. Self-stimulatory behaviors relate to one of the ways through which autistic adults express distress caused by pain and/or discomfort, according to some autistic participants who differentiated cure of health problems common among autistic individuals from ‘cure of autism.’ Self-stimulatory behaviors were also strategies to cope with uncomfortable

Sensory sensitivities. Sensory sensitivities have been suggested as one of the key characteristics of autism, but it was included as a diagnostic criteria in DSM only from its 5th (2013) version, which is the most recent DSM. More than one third of the diagnosed participants (8) mentioned their sensory sensitivity issue as one reason that they consider themselves to be on the spectrum, and four of them stated that issue as the first reason. A diagnosed participant’s answer started with their sensory sensitivity issue: “I have severe sensory processing difficulties (sound sensitivity, auditory processing problems, food aversions, hypersensitivity to touch). […]” Another diagnosed participant answered, “I have numerous autistic traits, including significant sensory and […].” Another participant answered that she took RAADS and she has since found that her “sensory perceptions, processing, and responses are more similar to those of other autistic people (regardless of their perceived 'functioning level') than to non-autistic people.” Most self-diagnosed participants (5) did not mention sensory sensitivities at all as a reason why they consider themselves to be autistic.

Communication difficulty. The age when one was diagnosed with an autism spectrum condition (or other related conditions) and being diagnosed with “autistic disorder” were closely associated with mentioning communication as the reason why one considers the self to be on the
spectrum. A participant who did not complete the survey was diagnosed at the age of three with an autism condition that the participant does not know, and answered, “I'm nonverbal; I have behavior challenges; I have severe social impairment.” Mastermind, who was originally diagnosed with PDD-NOS at the age of four and later diagnosed with Asperger’s syndrome at 15 years old revealed a particularly strong sense of alienation, which shows lack of communication with others: “I consider myself to be on The Autism Spectrum because I feel like I am an outcast of society.” Participants who were diagnosed as an early teenager mentioned difficulty initiating a conversation: “Because it's hard for me to start a conversation with other people”; “As a child I did not speak that much. I probably did not understand on what people were saying.” A participant who was diagnosed with autistic disorder at the age of 19 included “sometimes speech just doesn't work” in their answer. Communication difficulty relates to difficulty in asking for changes or help that I will report later as an autism-related characteristic that exacerbates the negative experiences of uncomfortable food environments. It also relates to difficulty in arranging to eat together.

**Self-diagnosis.** Several participants noted that they were self-diagnosed before their official diagnoses (e.g., “I was self-diagnosed before I was diagnosed professionally”; “I actually sought an evaluation because I read about autism as a young adult and realized that everything I was reading described my life”; “my only and elder sibling was Autistic and i realized at a young age that we shared traits”). A participant described the moment she realized she is autistic before her official diagnosis:

The first time I took the RAADS, I cried - because it was the first time in my life anyone had asked me questions that demonstrated any kind of awareness of how *I* perceived

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15 The asterisks (*) were used by the participant to emphasize the word, “I.”
the world. I've since found that my sensory perceptions, processing, and responses are more similar to those of other autistic people (regardless of their perceived ‘functioning level’) than to non-autistic people. Put another way, I am more like every autistic person I know than I am like any non-autistic person I know.

In addition to those who noted that they were self-diagnosed before their official diagnoses, there could be more diagnosed participants who self-diagnosed first but did not mention that answering this question, which is not specifically about self-diagnosis. For example, Loren did not mention in the survey that they was first self-diagnosed, but later said in the interview that their diagnosis was “underwhelming because [they] was already pretty sure.”

Online autism quiz results were mentioned also by two self-diagnosed participants, Tony and Alex, as a part of the reason they consider themselves on the spectrum. In the survey, Tony mentioned that his Aspie Quiz results as well as the criteria for autism spectrum disorder in DSM-5 made him consider himself to be on the spectrum:

I fit the criterion of DSM-5, I'd scored 'You are most likely an ASPIE on ASPIQUIZ. I fit many of the general characteristics, don't care about sports, Poor ball skills, IQ98.8 percentile on CTMM\(^{16}\), proctored by Mensa, I've been picked on my whole life, I don't understand how to make friends or meet potential mates, But I have very good language skill, I'm well coordinated, I relish change... go figure!

He later said in the interview that he believes he was misdiagnosed with bipolar and he is autistic. Alex largely echoed Tony’s answer:

Recently I encountered someone close to me taking an online test for autism and after reviewing some of the questions I felt it necessary to take the quiz myself. According to

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\(^{16}\) California Test of Mental Maturity
the quiz's results I was 'Very/Highly likely' to be on the spectrum. After much research, I believe I may have been misdiagnosed with depression, adhd, and social anxiety. I also believe a contributing factor to my misdiagnosis is the fact that I am a female.

Another self-diagnosed participant also mentioned DSM-5. He answered that he has “recognized [himself] in depictions of autism since childhood, and also [meets] the DSM-5 criteria for autism (social communication deficits, repetitive behaviors, odd sensory response patterns, etc.)” Three other self-diagnosed participants heard from someone that they seem to be on the autism spectrum. A self-diagnosed participant who lives in a sober house answered that her case worker suggested she is autistic, and listed some of the ‘symptoms’:

I had a case worker ask me if I had been diagnosed with it (I have been diagnosed with depression and thought disorder). Some of the 'symptoms' I have include thinking in pictures and being completely unaware of societal norms. I've never been able to 'read' people or situations, although it has gotten better over the years.

Another self-diagnosed participant had issues with social norms, in addition to having difficulty in social interaction: “It's difficult for me to be around people and I often can't understand the ways they live. I feel I'm quite different from them and life is too uncomfortable and difficult for me” Drew’s answer was very short: “Issues with empathy, charisma and self-awareness.” But they later said “Yes” to 29 out of 35 reasons by Lydia Brown, a diagnosed participant. Lydia (L. Brown, 2015) posted their answer (see Appendix F) to this question on their blog17, Autistic Hoya, as well “just in case it's helpful to anyone who might be out there questioning and

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17 Lydia is a survey participant, which means their responses must stay anonymous as well as confidential according the informed consent form of this research. By directly quoting the participant’s answer, which is posted on their non-anonymous blog, I risk breaking the consent. With written permission from them, I mention that this answer is posted on their blog as well. In order to protect their privacy, I will not associate this answer to their other answers that have not been disclosed through their blog. Drew went through Lydia’s list on the blog after Lydia gave me permission to mention that their answer is posted on the blog.
wondering whether they might be autistic.” Many commenters to the post strongly related themselves to the post regardless of whether they were diagnosed or had been wondering they might be autistic. *Their* list of reasons why *they* thinks *they* is autistic is insightful. Drew enjoyed going through Lydia’s list much more than answering the RAADS-14 questionnaire. The six reasons from Lydia’s list that did not apply to Drew were the following: occasionally losing the ability to produce oral speech under extreme stress; stimming; being extremely detail-oriented; relying on the scripts, having vivid dream (Drew dreams only a few times a year because *they* usually does not reach deep sleep to dream); tending to do activities the exact same way all the time; re-reading or re-watching entire books or movies or TV shows – or specific scenes in them.

**Autism diagnoses.**

*Names of diagnoses.* According to DSM-5 (APA, 2013), ‘autism spectrum disorder’ is a single diagnostic category. Regarding ‘Social communication’ and ‘Restricted, repetitive behaviors,’ the DSM-5 diagnostic criteria includes three “functional levels” that differ in terms of the degree to which one requires support: *Level 1,* which requires support; *Level 2,* which requires substantial support; and *Level 3,* which requires very substantial support. Two years after the DSM-5 was released, the participants in this research were asked to report their (or their autistic adult children’s) most recent autism diagnoses. Autism diagnoses of most diagnosed participants and diagnosed adult children were based on DSM-IV. Although support needs in the DSM-5 are not meant to be used as diagnostic classifications, two participants reported that they were diagnosed with ‘Level 1 autism spectrum disorder’ and one with ‘Level 3 autism spectrum disorder’; a participant, who reported that she was diagnosed with ‘Level 1 autism spectrum disorder’ and participated in the interview phase as well later, verified that her diagnosis is “Autism Spectrum Disorder 299.00 (F84.0)” and the functional levels for her ‘social
communication’ and ‘restricted, repetitive behaviors’ were both Level 1. Asperger’s disorder, which does not exist as a separate autism diagnosis anymore in DSM-5, was the most common autism diagnosis among the diagnosed participants (nine out of 23 when incomplete responses are excluded; 12 out of 27 when incomplete responses are included). It was also most commonly

**Autism Diagnoses**

![Autism Diagnoses](image)

*Figure 1. Recent autism diagnoses of autistic adults.*

Excluding five diagnosed participants who did not complete the online survey, the total number of autistic adults was 31: 23 diagnosed participants, six self-diagnosed participants and two diagnosed adult children.
implied as assumed diagnosis among the six self-diagnosed participants. The next most commonly reported diagnosis was autistic disorder: four from diagnosed participants and one from a parent of diagnosed adult child. Although all autistic participants were adults, three of them answered that they do not know their autism diagnoses; they were all first diagnosed with an autism condition as a child or as an early teenager, and one of them did not complete the survey. Two participants have been diagnosed with “Level 1 autism spectrum disorder”; one of the two was originally diagnosed with Asperger’s disorder in 1995. Other answers about the diagnoses were from the rest of each different participant: “Level 3 autism spectrum disorder”, pervasive developmental disorder not otherwise specified (PDD-NOS), high functioning autism, autism spectrum disorder, ‘either PDD-NOS or Asperger’s,’ unimportant, and ‘autistically impaired’. Out of the 31 autistic adults, three received two different autism diagnoses.

Age at the time of diagnosis. Approximately three quarters (17) of the diagnosed participants who completed the survey were adults when they were first diagnosed with an autism spectrum condition. The median of the diagnosed participants’ ages at their first time autism diagnosis was 22. Both of the two diagnosed adult children were all diagnosed when they were five.

Ritvo Autism and Asperger Diagnostic Scale-14 (RAADS-14). The RAADS-14 (Eriksson, at al., 2013) scores of the autistic participants were similar to those of its developers’ autism spectrum sample, and there was no significant difference between the diagnosed participant group and the self-diagnosed participant group in terms of their RAADS-14 scores. In the sample of the developers, the median score for autism spectrum disorder (ASD) was 32. A score of 14 was suggested as a cut-off score for ASD because a cut-off score of 14 or above reached a sensitivity of 97% in their ASD sample. The median score of 31 autistic participants,
including two diagnosed participants who did not complete the survey, was 36. Excluding two diagnosed participants who completed the RAADS-14 but did not complete the entire survey, both the median score of the 23 diagnosed participants and that of six self-diagnosed participants were same 35. Except Daniel, who scored 12, all of the 29 participants who consider themselves on the autism spectrum scored above 14. The reason why Daniel scored low despite having been diagnosed is at least partly because the participant was critical about the meaning of the word, people, in the RAADS-14 questionnaire. The participant provided a detailed critique on the RAADS-14 regarding the issue when asked to critique it in the survey:

Most of the questions talk about social interaction, but fail to specify the neurotype of the other person being interacted with. Social ability and social success are very different depending on whether the two people have the same neurotype or two different neurotypes. These vague questions are bad data practice for not only this survey but also the RAADS itself. I chose to answer all questions as though phrases like 'other people' were replaced with 'other autistic people'.

Many other participants also criticized the scale questions’ vagueness and assumptions. Although I provided the chance to do so as a way to help them release any frustrations they would have while answering the questions, their critical comments are noteworthy for practical reasons. Two issues that were frequently raised by participants were well summarized by another participant’s critique:

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18 The participant was different from other participants in some other ways as well. Unlike other participants, the participant wrote “Unimportant” to a question that asked to specify the participant’s autism spectrum diagnosis and did not answer to a question about the year of diagnosis. The participant also chose online video as a preferred interview mode while all other interview participants chose email interviews as their preferred interview mode. The participant decided not to answer some interview questions that used the term, diagnosis, because the person believes autism is not a disease that can be diagnosed.
They're insufficient because (1) they only focus on social interactions with people, and assume social interactions with non-autistic people without accounting for social interactions between autistic people; and (2) do not allow the options of 'most of the time' or 'some of the time' as gradients in between the options of 'true' (assuming always) or 'never.'

Drew originally did not provide any critique on the RAADS-14 questionnaire while taking the online survey. However, after answering the questionnaire one more time to see if it would generate the same result, they made many critical comments. They echoed Daniel’s critique on the RAADS-14 for its “vague” questions and assumptions. They particularly criticized its lack of specificity. For Question 3: ‘It is very difficult for me to work and function in groups,’ they responded:

Working in groups itself is not difficult. I’m fine with working in a group, talking with people. Things happen when you work with people. But if I work in a group one day, I can’t work in a group next day again because I’m depleted. I can’t work in groups every day.

They wondered about the frequency of group work the developers of the questionnaire meant in that question. For Question 14, ‘I get extremely upset when the way I like to do things is suddenly changed,’ Drew, who thinks Arabic is one of the most difficult languages to learn for English speakers, responded, “Everybody does. Who doesn’t? Be more specific. What kind of change? Let’s say the [English] alphabet suddenly changes to Arabic. Everybody will be so upset. There will be a riot in the street.” They criticized Question 4, ‘It is difficult to figure out what other people expect of me,’ for its assumption: “I don’t even try to figure out. What is [this question] talking about? This question assumes I try. Too much prejudice!” Reading Question 13,
‘I take things too literally, so I often miss what people are trying to say,’ they said, “Yes, like these people who developed this questionnaire. I don’t understand what they are trying to ask. They want to ask so many questions in one question. If they put them in separate questions, it could be easier.” They said they had very quickly marked answers because they was “really annoyed by this nonsense.” As Daniel criticized having this RAADS-14 is a bad practice for my data collection, Drew said RAADS-14 was a bad part of my online survey.

**Demographics.** Demographic information of autistic adults (23 diagnosed participants, 6 self-diagnosed participants and 2 diagnosed adult children) and parent participants (2) is reported below. Demographic information includes age, gender, education, income, employment, ethnic background, marital status, living arrangement and blogging. Under the subtitle of ‘Autistic adults,’ I report both that of 29 autistic participants and two diagnosed adult children, whose information is reported by their parents.

**Age.**

*Autistic adults.* Autistic adults ranged in age from 19 to 66. The average and the median of the ages of the autistic adults were 33 and 28, respectively.

*Parents.* Parent participants’ ages were in or about middle age.

**Gender.**

*Autistic adults.* Among the 31 autistic adults, the majority of them were those who are females or whose gender assigned at birth were females. Twenty were reported as female, five were male and six were other gender (genderqueer (2), non-binary (2), agender (1) and gendervague (1)). All autistic participants who identified their gender as other gender were diagnosed participants. All self-diagnosed participants identified their gender as either male (3) or female (3). All diagnosed adult children were reported as either male (1) or female (1) by their
parents. The rate of diagnosed participants who do not conform to the typical gender categories in this study (more than a quarter) was high, which is in line with high gender-nonconformity rates among individuals with autistic traits (Jones et al., 2012).

![Gender of the autistic adults](image)

**Figure 2. Gender of the autistic adults**

*Parents.* All three parent participants were females.

*Education.*

*Autistic adults.* Autistic adults, including diagnosed adult children, in this study were highly educated, not representing the general autism population (Shattuck et al., 2012). The reason why their education level is higher than the general autism population might be partly due to the large number of participants with a diagnosis of Asperger’s disorder. All of the autistic adults had a high school level diploma, and most of them (25 out of 29 in total; 19 out 23 among diagnosed participants) received at least some college level education: a number of them received more than college level education, three have achieved Bachelor’s degrees, three are current college students, one has achieved an associate’s degree and one took some college courses. The highest education level achieved by the largest number of the participants was Master’s degree (seven out of 29 in total; five out of 23 among diagnosed participants). Eight autistic participants received at least some level of doctoral education: three diagnosed participants were current doctoral students, three diagnosed participants have received Doctor of
Law (JD) degree, and two self-diagnosed participants have received other doctoral degrees (e.g., Doctor of Philosophy (Ph.D.), Doctor of Medicine (MD)). The two diagnosed adult children received a high school diploma, and one of them is presently in a transition program that teaches vocational training skills.

Parents. All parent participants were college educated. Two have achieved a Bachelor’s degree and one, whose diagnosed son also participated, has achieved a Master’s degree.

Figure 3. Education of the autistic adults

Income.

Autistic adults. Although the autistic participants were highly educated adults, a number of them were low-income and some were supported by their families. The number of the autistic participants who answered that they have annual income of less than $25,000 (12) was the highest. Five out of 29 autistic participants answered that they do not know their income, while they had another option, ‘I do not wish to say.’ Even when it is considered that six of them were
currently either undergraduate or graduate students, whose income are generally lower than $25,000 (c.f., two student participants reported that they work full-time; one receives between $25,000 and $49,999 and the other receives between $75,000 and $99,999), income of the autistic participants in this study was lower compared to that of the general population with the similar education levels. The two adult children were financially supported by their families, similar to a few other autistic participants.

Parents. Three parent participants’ income varied largely based on their education levels and marital statuses.

![Figure 4. Income of the autistic adults](image)

**Figure 4.** Income of the autistic adults

**Employment**

Autistic adults. The autistic adults’ low income level was directly related to their high unemployment or underemployment rate, which is a serious issue among many individuals on the autism spectrum (Shattuck et al., 2012). Out of 15 non-student diagnosed participants, three worked part-time, three were currently not working due to disability, and one worked in her

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19 Participants were allowed to choose more than one answer option.
residential facility without knowing her income. One diagnosed participant was a part-time student and part-time employee, and was seeking public assistance: “I'm employed part-time but am applying for SSI because work is so precarious for me. I need to start getting more regular income.” One diagnosed participant has a doctoral degree and was seeking employment. One diagnosed full-time student wanted to do a summer internship but could not find a position. A self-diagnosed participant with a doctoral degree was not working for reasons other than disability, including a health reason. Another self-diagnosed participant was working in a temporary position that pays less than the person’s previous temporary position from ten years ago. One self-diagnosed participant was presently working as a part-time intern and seeking employment. The only retired participant was a self-diagnosed participant.

Parents. A parent whose daughter goes to a vocational school was working part-time. A parent whose son was currently not working due to disability was too currently not working due to disability. A parent whose son participated in this research as well was working full-time but on a leave of absence.
**Figure 5.** Employment of the autistic adults

**Ethnic background.**

*Autistic adults.* The majority of the 31 autistic adults were white/Caucasians (23) or mixed (4). While most participants who answered that they are white or Caucasians did not further specify their ethnicity, the most frequently specified ethnicity was Jewish (4), which was either described as Ashkenazi or Eastern European Jewish. A participant specified that the person’s ethnic background is Autistic, though the person wrote in the person’s blog about *them* often self-identifying as white and being Jewish and Latino. Three autistic participants answered that they are Asian or Asian-American. None of the autistic adults were reported as black/African-American or Hispanic. The autistic adults’ ethnicity statistics in this study somewhat reflect the general autism population in the US, where white children are more likely to be identified with an autism spectrum condition than black or Hispanic children (Mandell et al., 2009).

*Parents.* Two parents were white and one parent was Asian.
**Marital status.**

*Autistic adults.* Autistic adults in this study were more likely to be single than adults in the general population, which is in line with the marital status statistics of the autism population (Howlin & Moss, 2012). More than half of both diagnosed participants and self-diagnosed participants were single. Among 31 autistic adults, 18 were single, five were married, three lived with partner, two were in a committed long-distance relationship and two were separated.

*Parents.* One was single, one divorced and one married.

![Marital status of the autistic adults](image)

**Figure 6.** Marital status of the autistic adults

*Living arrangement.* The autistic adults in this study were less likely to live a partner or a spouse than the general population. The answer option ‘Living independently’ was most frequently chosen. Compared to the general autism population, they were more likely to live independently or live with a partner or a spouse (Howlin & Moss, 2012). Several diagnosed participants were ‘Living together with their parent(s)’ all the time (4) or “part-time” (1). None of the self-diagnosed participants was living with their parents, and half of them were ‘Living independently.’ All diagnosed adult children were ‘Living with their parent(s).’ One diagnosed participant was living in a residential facility for individuals for neurological conditions. One self-diagnosed participant was living in a sober house.
Figure 7. Living arrangement of the autistic adults

**Blogging.** Fourteen out of 23 diagnosed autistic participants and one out of six self-diagnosed participant were bloggers. All but one of the diagnosed participant bloggers blogged about autism. The self-diagnosed participant blogger did not blog about autism. None of the diagnosed adult children or parent participants were bloggers.

**Characteristics of Interview Participants**

Out of 32 participants who completed the online survey, 11 participated in the interviews. Eight participated in the online interviews and three participated in the in-person interviews. With regards to relationship to autism, five participants were adults who have officially received an autism diagnosis, three are adults who are self-diagnosed and three are parents of diagnosed autistic adults (see Appendix G for detailed case histories of interview participants).

Four diagnosed adults, two self-diagnosed adults and two parents participated in online one-on-one interviews. The mode of the interview in which each participant participated was chosen based on each participant’s preference. Most of the participants preferred an email interview. A few of the diagnosed participants said they are fine with an online phone interview.
as well though they preferred an email interview. Except Loren, who participated in an instant messaging interview, all of them participated in email interviews. Tony shared some very personal answers via mail as well as email.

There were three in-person interview participants: Mastermind and his mother, and my friend, Drew.

*Table 2*. Numbers of interview participants by interview types and participant groups

<table>
<thead>
<tr>
<th>Interview types</th>
<th>Diagnosed</th>
<th>Self-diagnosed</th>
<th>Parents</th>
<th>Total</th>
</tr>
</thead>
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<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Instant messaging</td>
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<td>0</td>
<td>0</td>
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<tr>
<td>Total</td>
<td></td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>In-person interview</td>
<td></td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total interview participants</td>
<td></td>
<td>5</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

*Table 3*. Interview types by participant

<table>
<thead>
<tr>
<th>Interview types</th>
<th>Diagnosed</th>
<th>Self-diagnosed</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online interview</td>
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<td>Alyssa</td>
<td>Tony</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Samantha</td>
<td>Alex</td>
</tr>
<tr>
<td></td>
<td>Instant messaging</td>
<td>Daniel</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Loren</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In-person interview</td>
<td>Mastermind</td>
<td>Drew</td>
<td>Mother of Mastermind</td>
</tr>
</tbody>
</table>
Beliefs that are involved in food consumptions, distribution and production are a key aspect of foodways, along with practices involving in them, according to Counihan (2008). Participants’ survey responses to a claim that certain diets ‘help with autism’ revealed their beliefs on the relationship between diet, autism and health. Their beliefs on the relationship varied according to their conceptions of autism, particularly the conceptions of whether autism needs to be cured and whether autism needs to be treated. Participants who are against the cure of autism strongly opposed to a claim that certain diets ‘help with autism.’ Most participants believed that autism is a way of being. Several participants who answered that ‘Autism is a disability’ emphasized that autism is a disability in our society due to lack of support rather than because autism is intrinsically disabled.

In this chapter, I will first detail participants’ conceptions of autism, which are related to their beliefs on the relationship between diet, autism and health. Then, I will report their responses to the claim that certain diets ‘help with autism,’ which revealed the beliefs.

Conceptions of Autism

In this section, I will first report participants’ responses to the key statements which are related to their beliefs on the relationship between diet, autism and health, among the 15 statements about autism (see Appendix H for their responses to the rest of the 15 statements); their responses to the key statements will be used when I analyze their beliefs on the relationship between diet, autism and health in the next section. I then report participants’ definition of autism, which elaborated their responses to the statements about autism.
Reponses to statements about autism. As mentioned in the method section, based on the literature regarding diverse conceptions of autism noted in the table below, along with blog posts written by individuals on the autism spectrum or their parents, I designed 15 statements about conceptions of autism. Participants’ responses to each of the 15 statements revealed their understandings of diverse dimensions of autism. Among them, I report responses to the statements: ‘Autism is a way of being,’ ‘Autism is a part of a person’s identity,’ ‘Autism needs to be cured,’ ‘Autism needs to be treated,’ ‘Autism is a disability’).

**Autism is a way of being.**

![Autism is a way of being chart]

*Figure 8. Autism is a way of being*

Most participants ‘Strongly agreed’ with the statement ‘Autism is a way of being.’ None of the participants ‘Disagreed’ or ‘Strongly disagreed’ with the statement. Most notably, all but one of the diagnosed participants ‘Strongly agreed’ (17) or ‘Agreed’ (5) with the statement. It should be noted that the participants’ response to the statement is very meaningful. Their notion that ‘Autism is a way of being’ was repeatedly revealed throughout this study with some variations.
Autism is a part of an individual’s identity.

Figure 9. Autism is a part of an individual’s identity

Most diagnosed participants agreed with the statement ‘Autism is a part of an individual’s identity.’ Particularly, more than two thirds of them (14) ‘Strongly agreed’ with the statement. The pattern of these responses is almost directly opposite to that of the responses to the statement ‘Autism needs to be cured.’ It is possibly because most diagnosed participants, who are the majority of the participants, consider someone’s identity should not and cannot be cured. The responses to the statement ‘Autism is a part of an individual’s identity’ are also in line with the answer “Because I am,” which was provided by several diagnosed participants as an answer to the open-ended question on why they think they are on the autism spectrum. I will introduce Daniel’s definition of autism later, which emphasizes their understanding that ‘Autism is a part of an individual’s identity.’ The number of self-diagnosed participants who chose ‘Strongly agree’ also was the highest. While the participants’ response pattern to this statement was similar to their response pattern to the statement ‘Autism is a way of being,’ there were a few participants who disagreed with this statement.
Autism needs to be cured.

![Autism needs to be cured](image)

Figure 10. Autism needs to be cured

Most of the autistic participants disagreed with the statement ‘Autism needs to be cured.’ Diagnosed participants were particularly ‘Strongly disagreed’ with the statement. Fourteen out of 23 diagnosed participants chose ‘Strongly disagree’ and five chose ‘Disagree.’ There were only two diagnosed participants who ‘Agreed’ with the statement and no diagnosed participant ‘Strongly agreed’ with the statement. No self-diagnosed participant ‘Agreed’ or ‘Strongly agreed’ with the statement, but they more tended to choose ‘Disagree’ or ‘Neither agree nor disagree’ rather than ‘Strongly disagree.’

Autism needs to be treated.
Figure 11. Autism needs to be treated

Diagnosed participants responded to the statement ‘Autism needs to be treated’ quite differently from that to the statement ‘Autism needs to be cured.’ While the number of diagnosed participants ‘Strongly disagreed’ with the statement was higher than that of those who chose other response options, more than two thirds of diagnosed participants chose ‘Neither agree nor disagree’ or ‘Agree.’ Most of the participants who ‘Strongly disagreed’ with the statement were the participants who are active autistic self-advocates. Self-diagnosed participants, too, were more positive to the idea of treating autism than to the idea of curing autism. All but one self-diagnosed participants did not ‘Disagree’ with the statement.

*Autism is a disability.*
All but one participant answered that autism is ‘Somewhat,’ ‘Mostly,’ or ‘Completely’ a disability. A self-diagnosed participant was not sure about whether ‘Autism is a disability.’ While most of the self-diagnosed participants answered that autism is ‘Somewhat’ a disability, diagnosed participants were more likely to answer that autism is ‘Completely’ a disability; almost half of diagnosed participants (11) answered that autism is ‘Completely’ a disability and almost one third of diagnosed participants answered that autism is ‘Mostly’ a disability. The reason why one considers autism a disability is not clear from one’s response to this simple statement, even though such a reason may reflect one’s conception of autism. Blog posts written by many diagnosed participants and their definition of autism below revealed that they think autism is a disability because the society is not designed to meet their requirements, reflecting that they are aligned with the social model of disability. Their answers to the question about ‘What autism is in [their] own words’ also revealed the same understanding. Because this current statement ‘Autism is a disability’ does not specify whether autism is disability because of the way the society is designed or a person on the autism spectrum is intrinsically disabled regardless of the way the society is designed, this statement does not accurately differentiate different understanding of autism. I suggest ‘Autism is intrinsically a disability’ as a better
statement to more accurately understand respondents’ conceptions of autism. In that case, answer alternatives should be ranged from ‘Strongly disagree’ to ‘Strongly agree’ and have ‘I don’t know’ option.

**Definition of autism in one’s own words.** Here I review survey participants’ definition of autism in their own words, which elaborated their responses to the statements about autism. Some responses from interviews that further elaborated one’s survey answer are included as well. Many participants defined autism using the following understandings: autism as a difference, autism as an identity, autism as a disability and autism as a deficit.

**Autism as a difference.** The word “difference” was the most common word in the diagnosed participants’ definition of autism (e.g., “A difference in the way my brain works. It colors the way I experience the world. I think differently, not wrongly,” “A difference in brain wiring and perception; reactions to the perceptions cause distinguishable patterns of behavior, which is what we're using for diagnostic criteria right now,” “A different way of thinking, feeling, and perceiving than the majority of people,” “I see, percieve [sic] and react differently than the pajority [sic] of the population”). Many participants more specifically defined autism as a neurological difference with strengths and challenges:

Autism is a condition characterized by both positive and negative aspects. The positive aspects of Autism are possessing extremely high levels of intelligence and academic functioning capabilities, along with being extremely intuitive and visual. The negative aspects of Autism are possessing severe impairments with interpersonal relationships involving other humans, severe deficits in common sense, severe sensory overload issues, and very poor regulation of emotions, such as low frustration tolerance.
Autism is a neurological condition associated with particular traits. Some of these can be disabling, such as my personal struggles with executive functioning deficits, while others may be neutral or even beneficial, such as a powerful memory.

While defining autism as a difference, many participants specifically used the term, brain (e.g., “A difference in the way my brain works. It colors the way I experience the world. I think differently, not wrongly,” “Autism is the word that explains how my brain and body interprets and interacts with the environment”).

Framing autism as a difference is in line with many participants’ answers that ‘Autism is a way of being’ and ‘Autism is a natural human variation.’

_Autism as an identity._ Autism was defined as an identity by several diagnosed participants who ‘Strongly disagreed’ with the statement that autism needs to be cured and ‘Strongly agreed’ with the statement that autism is a part of an individual’s identity. One participant defined autism as “Me.” Her answer was very short but as powerful as another participant’s following very articulate definition:

Autism is one of the many variants of human neurology, within the natural diversity of humans. More specifically, it is one of the overarching brain types - ‘pervasive’ as the medical community calls it - meaning that changing a brain to or from autism, if that were possible, _would be the death of one person and simultaneously creation of a new_ different person. Perception, thought, expression - every aspect of living as a human can be filed into one of those three categories, and autism can be identified in all three of them. This is distinct from situational or surface-level forms of neurodivergence, such as anxiety or a seizure. Neither the medical community nor the neurodiversity movement
have mapped out what is pervasive and what is not, but it is clear at this point that autistic and neurotypical are two of the brain types that are pervasive. [emphasis added]

In contrast, Abby\textsuperscript{20}, a diagnosed participant who ‘Strongly agreed’ with the statement that autism needs to be cured did not agree that autism is a part of her identity by contrasting her definition of autism with what she sees in others:

[…] I find it interesting that many autistics I know who take meds for their ADHD symptoms would not take a pill for their autism, if such a medication existed. Why is autism seen as integral to one's identity but ADHD is something that we're more comfortable with 'fixing'? […]

\textit{Autism as a disability}. Following the social model of disability, most participants whose definition of autism included autism as a disability noted that autism is a disability due to the society which does not properly accommodate requirements of autistic individuals:

Autism is a pervasive developmental and cognitive difference and disability (because society is really badly not designed for us.) It affects the ways we process sensory information and language, and that tends to affect, well, everything else ever.

Autism is a neurological framework that defines and influences how an autistic person communicates, develops relationships (of any kind with other humans), experiences/expresses emotions or ideas, thinks, and learns. In the context of our society, Autism is a disability.

\textsuperscript{20} Abby did not participate in the interview, but I assigned a pseudonym to her because she provided a very detailed definition of autism and parts of her answer are frequently quoted in this section on the participants’ own definition of autism.
Autism is a difference in information processing. It is a disability as the world is not set up for autistics. Many autistics simultaneously have fantastic strengths and face severe challenges, often within the same day.

However, Abby did not differentiate disability from disorder and stated that accommodations would not resolve her autism disorder. While the diagnosed participants who consider autism a disability due to the unsupportive society did not claim that accommodations would allow an autistic person to live without any disability, she was concerned that the emphasis on accommodations might result in less efforts to resolve autism’s ‘unequivocal’ disorder aspect:

[…] In terms of the difference versus disability debate, my experience has been that my autism is unequivocally a disorder. Some autistics find that accommodations alone relieve the source of their difficulties, but even in a perfect world my autism would still trouble me. You can give me I-phone apps and organizational coaching, but I will still have problems getting myself ready for my day and ensuring I have everything I need (to the point that I have found myself in very vulnerable situations that threaten my wellbeing). A world more understanding of my autism would be great, but this wouldn't take away my clumsiness (which has seriously endangered my life at several points!).

There are certain deficits which can't be relieved by accommodations. I like that there is a growing movement for autism acceptance, but I do worry people perceive understanding and accommodations as a magic wand. For many (though not all) autistics, there will still be distress.[…] It is wonderful to celebrate autism, but since each person's autistic experience is unique, it is important to understand that for some autistic people - such as myself - the frustrations of autism outweigh the benefits, even with all the support in the world.
Autism as a deficit. Participants who agreed to the statement that ‘Autism needs to be cured’ tended to focus more on the deficit side of autism (e.g., “Autism is a disability that caused a person to have verbal problems and affects his or her brain”). Abby, who thinks autism is mainly a deficit, believes that there are different kinds of autisms with different causes, and hopes that science may succeed in finding autism cures:

I believe in the idea of autisms - the possibility that autism is not one condition with a singular cause, but a multifactorial cluster of challenges which tend to accompany and exacerbate each other. This is why different autistics have different profiles of symptoms. For me, my most distressing challenge is my wildly writhing stims and a pervasive cloud of executive dysfunction. For another autistic, their movements and cognition might not be as affected but they may have greater difficulties making eye contact and regulating their tone of voice. I think the reason why researchers have not been able to implicate a particular cause of autism is because there is none - perhaps autism can't be attributed to a specific gene, region of the brain, or environmental issue because the diverse spectrum of challenges aligns with a diverse spectrum of causes. I have a brain cyst, which I sometimes wonder if it could be a source of my symptoms. Other autistics may have abnormalities in their corpus callosum, elevated (or suppressed) levels of certain transmitters, a genetic syndrome, or an overgrowth of certain proteins in their brain. Maybe someday science will be able to determine the interaction of causes with more precision, but it doesn't look like we're at that point yet. […]

Samantha, who agreed with the statement that autism needs to be cured, thinks autism needs to be cured because of its deficits. In an interview, she said, for her, cure of autism means assisting one to be less affected by autism symptoms, most notably difficulty in social interaction. The
reason why she takes anti-anxiety meds is to avoid meltdowns when she needs to deal with people at work. She hopes for better drugs or therapies that would assist her with communication, executive functioning and social interaction challenges related to autism. She said that she currently has to produce and work twice as hard as an average person to earn promotions because of the issues; thanks to her high IQ, and creativity, which involves no preconceived bias and her complete outside of the box cognitive style, she has earned promotions, but she “would love to lose that nebulous social skills glass ceiling.”

Summary of conceptions of autism. In this section, I detailed autistic participants’ conceptions of autism, which are related to their beliefs on the relationship between diet, autism and health. While there were several participants who answered that ‘Autism needs to be cured,’ no participant disagreed with the statement that ‘Autism is a way of being’ whether they were diagnosed participants or self-diagnosed participants. According to participants’ responses to the statements about autism and their answers to the question about ‘Autism in [their] own words,’ conceptions of autism of most diagnosed participants greatly differ from those of medical model of autism. From their responses to the statements, most notably, it was found that most of them think that autism is a way of being, autism is a part of a person’s identity, autism is natural human variation and autism does not need to be cured. They were also less oppositional to the statement ‘Autism needs to be treated’ than to the statement ‘Autism needs to be cured.’ Some of this reduced opposition may be in recognition of the many bodily disorders that come along with “Autism,” rather than autism itself. Autism was also considered as a disability by most of the diagnosed participants and some of them explained that it is because society is not designed to support “disabled” people. Here again, there may be complications because of the politics of needing to be labeled “disabled” in order to receive desired treatments for medical conditions
that come along with “Autism.” On the other hand, the findings indicated that there are some diagnosed participants who do not agree with the majority of the diagnosed participants. The number of self-diagnosed participants was very small but their answers implied that they are generally less likely to be strongly opinionated regarding conceptions of autism than the diagnosed participants.

**Responses to a Claim that Certain Diets ‘Help with Autism’**

In this section, I will report how participants’ conceptions of autism are related to responses to a claim that certain diets ‘help with autism,’ which revealed their beliefs on the relationship between diet, autism and health. Participants’ responses to the two statements about autism, ‘Autism needs to be cured’ and ‘Autism needs to be treated,’ will be used when I explore the relationship between participants’ conceptions of autism and their responses to the claim. I chose these two statements based on Kapp and colleagues’ (2012) finding that autistics and people who were aware of the neurodiversity movement opposed to cure, which was different from the medical model of autism, but not consistently opposed to treatment. I will organize participants’ responses to the claim that certain diets ‘help with autism’ according to their responses to the two statements, ‘Autism needs to be cured’ and ‘Autism needs to be treated.’

Young participants who are diagnosed and blog about autism tended to ‘Strongly disagreed’ with both cure of autism and treatment of autism and had a very strong objection to the claim that certain diets ‘help with autism’ (e.g., “Bull! Those diets are silly and they don't do a thing”, “Hahahahaha!”).

Daniel, Lydia and Alyssa, three participants who are actively involved in Autism Self Advocacy Network (ASAN), ‘Strongly disagreed’ with both cure of autism and treatment of
autism, raised an issue about the word “help” in the question as well, and differentiated helping an autistic person improving health from helping with autism. Daniel critiqued,

Framing a goal or outcome as 'helping with autism' is already working in a dangerous and counterproductive model. That phrasing presents autism as a separate entity from the autistic person, which it isn't, and assumes that it should be gotten rid of, which it shouldn't. Does a change of diet help some autistic people be healthy in their own ways? Yes, absolutely. It is healthy to maintain a good relationship with food, and some autistic people also have non-autism food issues such as allergies. Do certain diets get rid of autism or make people 'less autistic'? No. They can't because that's impossible, because that doesn't make sense. Even if it did make sense for a person to become 'less autistic' and even if it were possible to make a person 'less autistic', it still wouldn't be ethical to try.

Lydia echoed,

Individual autistic people may find that specific diets help them with feeling comfortable in their own body or regulating their own sensory input or anxiety levels. Overall, I don't believe that any specific diet 'helps' with autism, especially because that assumes that autism necessarily needs to be 'helped.'

Alyssa differentiated ‘autistic ways of showing distress’ from ‘autism’:

I think those people are making two major conflations. The first is between 'autism' and 'autistic ways of showing distress.' (Most of the self-harming stims tend to be signs of distress, not our natural states, for example.) The first is between any other medical stuff we might have and autism. I have (fairly mild) gastroparesis, and because of that I can't have too much fiber. If I have too much fiber, I get distressed, because it's uncomfortable.
However, my stomach issue is not the same thing as my being autistic. So a certain diet might help a certain person, but saying the diet helps with autism involves two big conflations of things that aren’t the same, plus it kind of assumes autism is a thing you need to 'help with' by reducing signs of. Yuck.

A diagnosed participant who ‘Strongly disagreed’ with cure of autism and ‘Disagreed’ with treatment of autism, considered worsening of autistic traits due to stresses caused by a certain silent food allergy, but viewed that removing such allergens from the diet only helps the person better deal with the environment:

I think that autistic traits can be worse when a person is stressed, overwhelmed, or in pain. (This is 100% true with me.) If someone has another condition, such as an undiagnosed food allergy, then to me, it makes perfect sense that changing their diet to not include that food will help them to cope better with the environment. HOWEVER, that does *NOT* mean that the diet change makes them not autistic. It just is helping the person by giving them another tool to successfully navigate the world.

Diagnosed participants who ‘Disagree’ with cure of autism but ‘Neither agree nor disagree’ with treatment of autism were highly aware of the notion of diets for autism and often clearly differentiated autism from medical conditions that are common among autistic people, most notably gastrointestinal (GI) issues (i.e., “I think that is bullshit. Autistic people often have GI issues and some diets help with those GI issues which result in better overall quality of life and therefore less 'autistic behaviors' related to discomfort etc”; “I think it's snake oil sold to desperate parents, and it needlessly restricts the food intake of kids who quite possibly already have food aversions and GI problems to contend with”;

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21 These asterisk (*) marks were used by the participant possibly to emphasize the word, ‘not.’
I think this is pseudoscientific garbage motivated by distrust of mainstream medicine and a New Agey ideology of "self-empowerment" to address illnesses or other conditions. Perhaps children with autism may have sensitive stomachs and benefit from diets that don't upset their digestion simply because they are more comfortable, but I do not think that diet has anything to do with autism itself.

A diagnosed participant who is sensitive to gluten ‘Strongly disagrees’ with cure of autism but ‘Agrees’ with treatment of autism and differentiated “helping with autism” from “helping with nausea,” based on her own experience; when her nausea was treated with a gluten-free diet, some areas of autistic traits reduced and some areas became more pronounced:

   Not with autism per se. My silent celiac diagnosis (via biopsy) and the subsequent elimination of gluten from my diet *did* help me focus better and do social scripts better, because I was no longer constantly willing myself not to throw up on whoever was talking to me. But it didn't 'help with autism.' (If anything, my stereotypically autistic behaviors like flapping and rocking got more pronounced, because I could do them without provoking my nausea.)

   In contrast, diagnosed participants who ‘Agree’ with both cure of autism and treatment of autism did not disagree with a claim that certain diets ‘help with autism.’ Two of them connected food to their autistic symptoms. Samantha briefly answered, “too much fat or sugar makes me feel sick,” without explaining her understanding of the relationship between autism, “too much fat or sugar,” and feeling sick in the survey. She later explained in the interview that she has serious GI track issues and she needs to avoid eating these foods, or her “autism symptoms worse[en].” She is neither diabetic nor hypoglycemic, but still affected by these foods. While she “doubt[s] very much if what she eats can make [her] autism better or worse (and most scientific
double blind studies support this),” she is convinced that not providing herself with regular nutrients in a form that she can tolerate will make symptoms worse, and she is “at risk for worse symptoms when she is hungry or tired”; she said, “The old adage HALT[—]don't get too hungry, angry, lonely, or tired[—]pretty much sums up my advice.” Abby wanted to try diets to “more comfortably manage” her symptoms of autism, and, like Samantha, noted the negative impacts of being hungry on several aspects of her difficulties related to autism:

If I had a better financial situation, I would definitely experiment with diets. I've always wondered if eliminating artificial ingredients or increasing levels of certain nutrients would help me more comfortably manage my symptoms. This is not to say that I attribute autism to dietary imbalances, but perhaps some tweaks could mitigate select challenges, even if this is only due to an increase in energy. Unfortunately I am working a minimum wage job on a part-time basis, so this doesn't easily allow me to purchase supplements, buy organic foods, increase my protein levels, or even eat regular meals. I oftentimes skip breakfast and/or lunch, and undoubtedly this impacts the presentation of my difficulties. I become more anxious when I am hungry, am prone to disassociate, and my clumsiness/cognitive issues are exacerbated. […]

Self-diagnosed participants, almost all of who ‘Strongly disagreed’ with cure of autism, seemed to be generally unaware of the notion on diets for autism or have positive opinion to the claim, though their answers were not as articulate as those of the diagnosed participants (e.g., “I was completely unaware of this notion, but can see this being a possibility,” “I think it is helpful in some aspects,” “worth trying”). For them, the word ‘help’ did not seem to trigger any phrases that are used usually in a negative context, such as, “getting rid of.” Alex, who ‘Disagrees’ with
cure of autism and ‘Agrees’ with treatment of autism, saw that notion as a possibility because she believes her health-related quality of life is maintained by her eating habits:

On days that I eat steamed vegetables with ginger and pinch of sea salt, I feel invigorated and clear minded. On days and days after when I eat four slices of cheese pizza I suffer from sinus congestion and feel emotionally apathetic.

Drew, who ‘Neither agrees nor disagrees’ with both cure of autism and treatment of autism, answered “worth trying,” because they, too, feels “bad” after eating pizza or pancakes whereas they feels very refreshed, both mentally and physically, after drinking green juice made of kale, carrots, celery, ginger and cucumbers. They said that after drinking green juice they does not even feels like drinking wine, which they often drinks when feeling depressed. Green juice also quickly helped them recover from feeling fatigue. One self-diagnosed participant, who ‘Disagrees’ with cure of autism and ‘Neither agrees nor disagrees’ with treatment of autism, disagreed with the claim but was familiar with the relationship between diets and GI issues that are common among autistic people: “[They] Can't say [that certain diets ‘help with autism’]; but certainly some diets can be unhelpful (creating higher levels of stress/agitation, or causing the sorts of gastrointestinal issues that autistic people are prone to”). A self-diagnosed participant, who ‘Neither agrees nor disagrees’ with cure of autism and ‘Agrees’ with treatment of autism, answered that “I am a vegetarian and eat healthy foods, but I haven't noticed a difference (compared to when I didn't pay attention to my diet),” revealing that she was not highly aware of the more commonly suggested but controversial diets for autism such as gluten-free diet or casein-free diet. Tony did not disagree with the claim although he exceptionally ‘Strongly disagrees’ with both cure of autism and treatment of autism as a self-diagnosed participant.
Regarding the claim, he answered, “If my chronic constipation is a result of my Autism, then vegetarian and chicken is best.”

Mastermind’s mother said she had done brief research on the effects of gluten-free diet on autistic people and Mastermind, who answered that he ‘Strongly disagrees’ with both cure of autism and treatment of autism, had done more research than she. After doing the research, he came up with the idea of going for gluten-free by himself and told her “Mom, I want to go with a gluten-free diet.” I asked her what she thinks about many autistic self-advocates’ opinion that if someone is autistic and allergic to gluten, the person might improve the person’s health by going for gluten-free but that does not mean that a gluten-free diet makes the person less autistic. While not being sure if a gluten-free diet may make someone less autistic, she shared her understanding that more physical issues and anxiety caused by any source would cause more autistic behavioral issues:

But, most of the people, this is what Mastermind researched and said, most of the people who are autistic are sensitive to gluten. I don’t know if a gluten-free diet makes someone less autistic, but if most of the people who are autistic are sensitive to gluten, it is worth trying. Autistic people have a lot of things going on. If the food, gluten, gives them trouble, then they will have more anxiety, they are not feeling well. Typically, they are physically not feeling well, also. There you go. There will be more behavioral issues.

In summary, participants who are against a cure of autism, generally opposed the claims that certain diets ‘help with autism.’ They differentiated autism from ‘autistic ways of showing distress,’ and ‘cure of autism’ from cure of health problems common among autistic individuals.
Summary

In this chapter, I explored autistic participants’ conceptions of autism and beliefs on the relationship between diet, autism and health. Their survey responses to a claim that certain diets ‘help with autism’ revealed their beliefs on the relationship between diet, autism and health. Their beliefs on the relationship varied according to their conceptions of autism. Participants who are against the cure of autism strongly opposed to a claim that certain diets ‘help with autism’; they differentiated autism from ‘autistic ways of showing distress,’ and ‘cure of autism’ from cure of health problems common among autistic individuals. Participants suggested that distress are a result of the over-stimulating environment, hunger, or health issues including pain, gastrointestinal issues, allergic reactions or sensitivities to certain foods. Regardless of their opinion on cure of autism and treatment of autism, most participants believed that autism is a way of being. Several participants who answered that ‘Autism is a disability’ also emphasized that autism is a disability in our society due to lack of support rather than because autism is intrinsically disabling.

The findings in this chapter on a belief aspect of foodways suggest that autistic adults need an environment where their autism-related characteristics are respected and their needs to access healthy food environments should be supported. However, many participants in this study were living in invisible food deserts according to the findings reported on the following chapter.
CHAPTER VI
LIVING IN INVISIBLE FOOD DESERTS

In the previous chapter on beliefs on the relationship between diet, autism and health, I reported that many autistic participants believe that autism is a way of being that needs to be supported; that some common health issues of autism may be helped by certain diets and some ‘symptoms’ of autism are consequences of or ways to express distress, which could be a result of the over-stimulating environment, hunger, or allergic reactions or sensitivities to certain foods. However, the food environments of my participants often did not accommodate their various autism-related characteristics. The findings below on difficulty in accessing ‘safe’ foods and accessing comfortable food environments suggest that autistic adults live in atypical food deserts.

Food deserts are commonly defined as areas where the availability and affordability of foods that may benefit health are restricted (Cummins, 2014). Food deserts have been studied in the context of the urban poor and their neighborhoods. Many autistic adults in this study were low-income and experienced typical negative aspects of food deserts. More importantly, I found that they also experience atypical food deserts, which I call invisible food deserts, due to social and physical environments that do not accommodate autism-related characteristics. Even the few high-income participants encountered invisible food desert moments for that reason.

I identified four characteristics of invisible food deserts experienced by autistic adults in this study: (a) limited availability of edible foods due to restricted diets; (b) ‘unsafe’ people who enforce unwanted social interactions or diets; (c) over-stimulating food places; and (d) food places’ hours of operation experienced as restricted. Negative experiences of the invisible food deserts were often exacerbated by the following: (a) limited financial resources; (b) difficulty in
asking for changes or help; (c) limited mobility due to lack of driving skills; and (d) challenges in cooking and growing food.

In this chapter, I will first briefly report responses to survey questions regarding food aversions, challenges in eating out (with others) and challenges while grocery shopping. I will then detail the characteristics of the invisible food deserts and the factors that exacerbate the negative experiences of the invisible food deserts that emerged as themes through a thematic analysis of interview responses.

Survey Responses on Eating and Grocery Shopping

**Food Aversion.** In order to understand autistic adults’ eating habits, I asked survey participants if there are any food types they (or their children) would rather not eat and the reasons. Most participants checked several types of foods. Options were ‘Fruits And Berries,’ ‘Greens,’ ‘Legumes,’ ‘Tubers,’ ‘Grains,’ ‘Poultry,’ ‘Fish,’ ‘Seafood (Non-Fish),’ ‘Beef,’ ‘Pork,’ ‘Eggs,’ ‘Dairy,’ ‘Nuts,’ ‘Not Applicable,’ and ‘Other.’ A large number of participants were vegetarians; ‘Seafood (Non-Fish)’ (13), ‘Pork’ (13), ‘Beef’ (12), ‘Poultry’ (9), ‘Legumes’ (9) and ‘Fish’ (8) were frequently checked. While Sally reported that there is no food that her daughter, Rose, would rather not eat, two other parents checked several foods as foods their autistic children would rather not eat. Mastermind’s mother checked fruits and greens in addition to most of the foods that he checked. Hannah reported that her son, Jason, would not eat pork, beef, legumes and dairy, which overlaps with other autistic participants’ responses. While there was no apparent difference between diagnosed participants and self-diagnosed participants in terms of the number of categories of food they would rather not eat, diagnosed participants generally identified more specific food items they avoid.
Figure 13. Food aversion

Challenges in eating out. Survey participants were asked what aspects of eating out make it hard to comfortably eat. Crowding was a situation that the largest number of the participants (20 out of 23 diagnosed participants, four out of six self-diagnosed participants) checked as a challenge when eating out. The next most frequently checked challenge was noise. The numbers of participants who checked noise and crowding were almost the same. Lighting was another challenge when eating out (15 diagnosed participants). Many diagnosed participants were low income and/or students, and price was the next frequently reported challenge in eating out for diagnosed participants (14). Of course, this is a factor in limiting the choices of places to the low-end, which exacerbates other problems as I will detail later. A lack of variety of food was an issue for the participants, especially for those who had a very limited diet. This was another issue of low-end eating. Smells of eating places bothered almost half of the diagnosed
participants (11). The aesthetic quality of eating places was indicated as a challenge when eating out by a large number of diagnosed participants (10). For nine diagnosed participants, the location of eating places was a challenge. Nine participants (seven diagnosed, two self-diagnosed) pointed out ‘Hours of operation’ as an issue. Store layout was chosen as a challenge by eight diagnosed participants but by no self-diagnosed participant. While ‘unwanted social interaction’ was not one of the options in the survey, many participants mentioned that issue in the survey.

**Figure 14. Challenges in eating out**

**Challenges in eating with others.** Autistic participants, particularly those who have been diagnosed, experienced many challenges while eating out with others. The challenges experienced by diagnosed participants were first reflected in the finding that almost a quarter of them (6) usually do not eat with others when they eat out. Even some of those who answered that they usually eat with others when eating out explained that they eat only with very close family or “safe” people (e.g., “Usually with my husband -- no problems,” “I wanted to mention that
having conversations during mealtime WOULD be difficult with most people, but I avoid eating out with those people. I only eat out with people who are safe or at least semi-safe people for me.”). Dietary restriction was checked as a challenge by the largest number of diagnosed participants, a little less than half of them (10). It was followed by “Difficulty in having conversations during mealtime” (9), “Not liking places where others like to go” (8), “Difficulty in arranging to eat together” (7), and “Not necessarily eating when others eat” (6). While none of the six self-diagnosed participants answered that the “Sounds of other people eating bother” them, five diagnosed participants answered that they are bothered by that. Other challenges experienced by diagnosed participants included not having people to eat together with, paying the bill, hating when foods touch each other, trouble eating with fork/dropping food and not liking to touch or bite into a big piece of food such as a pizza slice or a sandwich.

![Difficulty in eating with others](image.png)

**Figure 15.** Difficulty in eating with others

**Challenges while grocery shopping.** ‘Crowding’ was the most frequently chosen challenge of grocery shopping. Nineteen diagnosed participants and four out of six diagnosed participants chose ‘Crowding’ as one of their challenges. ‘Noise’ (17 diagnosed, 1 self-
diagnosed), ‘Lighting’ (16 diagnosed, 2 self-diagnosed) and ‘Store layout’ (14 diagnosed, 2 self-diagnosed) were the next frequently chosen challenges. ‘Location’ and ‘Variety of food’ also were key areas of challenges. Other aspects of groceries, such as ‘Aesthetic quality,’ ‘Smells,’ and ‘Price,’ were issues to a number of participants. For some participants, ‘Air quality’ and ‘Hours of Operation’ were also problematic.

![Challenges while grocery shopping](image)

**Figure 16.** Challenges while grocery shopping

**Characteristics and Experiences of Invisible Food Deserts**

One of the most striking findings in this study was that many participants mentioned that they chose not to eat and chose to “go hungry” because the food and food places were “not doable” in many cases. They were living in invisible food deserts. Based on the responses from the survey and interviews, I identified living in invisible food deserts as a main theme and each of the following four characteristics of invisible food deserts as subthemes.
**Limited availability of edible foods due to restricted diet.** While most of the autistic adults in this study were not on any restricted diet for autism, almost all of them had aversions to various foods. For individuals with serious food aversions, even food environments where the availability and affordability of food that may benefit health is not restricted may be experienced as food deserts for them if they cannot access edible foods. Jason’s aversion to certain foods, which seemed stronger than most other autistic participants, illustrates how one’s food aversion leads to a food desert experience. Hannah described Jason’s aversion:

He eats at fast food restaurants every day, he will only eat Pepperoni Pizza or chicken strips. If he does eat at home he will opt for pasta (no sauce). His food is limited, but he refuses to eat anything else. Offer him something different and he acts as if you’re trying to poison him or something. He also notices if his food is somehow different (a restaurant changed the oil they used to cook with once and he stopped eating their chicken).

In this section, I will detail participants’ restricted diets, integrating responses to open-ended questions and interview questions. Participants’ diets were restricted mainly due to their sensory sensitivities (i.e., texture, taste) and feeling disgusted, both of which resulted in food aversion, and due to other reasons such as health reasons, ethical reasons and medical reasons. I will then illustrate experiences of invisible food deserts of participants whose diets are limited.

*Sensory sensitivities.* The most frequently mentioned reasons of food aversion were related to sensory sensitivity issues, most notably texture and taste.

*Texture.* Texture was the most salient reason of avoiding various kinds of foods (e.g., “Texture mostly; wriggly or squishy things that aren't sweet, gristly or stringy meat, rubbery anything or chunks in something that's not supposed to be chunky,” “I despise the textures of eggs, tubers, and seafood,” “Most are texture aversions – Fruits and berries, greens and eggs”).
Particularly the texture of eggs and meat were frequently mentioned (e.g., “Eggs are a sensory issue because the texture is bad,” “meat that is thick or sinewy”). Texture was also often mentioned in the “other” section for the question about types of foods one would rather not eat (e.g., "mixed texture,” “slimy,” “[…] I do not like the texture of raw vegetables. There are many thing I do not like the texture of so this is a little to [sic] broad for me.”). E, a diagnosed participant, wrote in more detail about her issue with texture, noting texture as the most important reason that she avoids a food:

I have no 'broad' food groups which I do not eat. However, I can name specific things that are within any of those groups. I have a very particular interaction with the texture of food, especially mealy textures (like carrots), or mixed textures, like quiche. I have a tough time with non-melted cheese, and pretty much anything that involves a lot of vegetables mixed together. (Unless it is cooked and served over rice, in which case, there's about a 30/70 chance I'll be able to eat it). Texture is the biggest reason that I won't eat a food.

Taste. Taste was the second most frequently mentioned reason that one avoids certain food. Many autistic participants avoided vegetables, especially greens for its taste (e.g., “Vegetables taste bad,” “My taste buds tell me that [greens] are not food,” “Because my mind is telling me that [green] is going to taste weird and nasty”). Seafood, too, was avoided by many because of its taste (e.g., “I've never liked the taste of much seafood or fish”). Some participants avoided eating meat because of its taste (e.g., “[poultry, pork and beef] taste awful”). In a section to make a critical comment on the survey, a participant also pointed out taste sensitivities as an

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22 The participant with an initial, ‘E,’ participated only in the survey, but allowed me to quote her blog posts. Because I often quote both her survey answers and blog posts, I call her ‘E,’ distinguishing her from other survey participants.
important reason for the person’s “autistic” eating disorder and asked for more autistic foodways research on eating disorder:

[…] Another topic I felt was missing from this survey is eating disorders. Participants should have the option to say they identify as having an eating disorder followed by a set of questions about how the nature of the eating disorder and how it impacts the use of foodways. My eating disorder doesn't have a name because it is an autistic eating disorder and aspects of autism that actually matter to autistic people are ridiculously under-researched. My eating disorder is similar to ARFID23: It involves not eating unless I'm presented with one of my favorite foods, which is a short list due to taste sensitivities.

**Feeling disgusted.** Some participants did not attribute the reasons they avoid eating certain food specifically to texture or taste but rather to feeling disgust, which may be a combination of several sensory stimulations (e.g., “[Greens and legumes] are yucky,”). Feeling of disgust was often mentioned regarding meat. For example, a diagnosed participant answered regarding meat:

Feeling the textures in my mouth causes a bad sensory reaction for me and makes me feel sick. I also avoid meat because, although I see nothing morally wrong with eating meat, I'm grossed out by the thought of putting a dead animal in my mouth. Before I became uncomfortable with that aspect, though, I also had problems with the texture of almost all kinds of meat.

Abby’s detailed narrative about how she is repulsed by meat is also noteworthy:

I've always found myself repulsed by meat. I am a vegetarian, not necessarily for ethical reasons but because everything about meat makes my stomach curdle: the sensation of

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23 Avoidant/restrictive food intake disorder
blubbery fat in my mouth, the fragments of blood vessels which inevitably get left behind here-and-there, the flavor of death, and the appearance of meat itself. While grisly brisket and pork disgusts me, oddly enough the meat which most perturbs me is lunchmeat: something about the suspiciously perfect curves, the uniform sheen, and the odor (am I really the only person who thinks that deli turkey smells like farts?) is a sensory overload for me. Elementary school lunchtime was undescrribably [sic] unpleasant for me, surrounded by friends with Lunchables or bologna roll-up's. (My obsessive nature is so strong to the point that for years I would avoid writing the word bologna, and I felt uncomfortable if someone would start talking about their friend so-and-so Maloney or visiting the Italian city of Bologna. When I would hear the phrase 'that's a load of baloney,' I would become paralyzed by discomfort). Maybe I would have been more social if I didn't have to constantly worry about looking away from my classmates' sandwiches. As an adult, I at least have the luxury of avoiding restaurants or other settings where I know lunchmeat is served. Sometimes I feel ashamed of my lunchmeat aversion. If someone casually mentions 'I'm going to go to the store to pick up some lunchmeat', I can no longer look at them the same way again. It's like the world is divided into two types of people: those who eat lunchmeat and those who don't. I know it seems preposterous - even to me - but no matter how hard I try I can't seem to shake this knee-jerk reaction. And it's not just lunchmeat which makes my nostrils close, my eyes withdraw, and my skin crawl; I find being in close proximity with sandwiches in general to make me really uncomfortable. I will eat shredded cheese or melted cheese, but I can't handle cheese in perfect geometric shapes, as in cheese slices or cuts of block cheese. The smell of bread also is enough to make me gag. Not just any bread - biscuits, dinner
rolls, and garlic bread are all fine - but the odor of sandwich bread, whether it is white or wheat.

Her reaction to lunchmeat was quite similar to Drew’s reaction to sausage. When asked about lunchmeat, Drew said they, too, is disgusted by lunchmeat and it smells like farts, confirming she is not the only person who feels some processed meat smell that way. They is also disgusted by seeing meat being cooked and does not like meat being cooked in the house. Before knowing about their aversion to meat being cooked, I brought them to a Korean restaurant and ordered Korean barbeque. As soon as a waiter began to cook the meat on the in-table charcoal grill, they felt so disgusted and asked the person to cook the meat in the kitchen and bring back when it is done.

While I have no basis for direct comparison, it seems likely to me that this emphasis on the sensory issues of texture, taste, and disgust is unprecedented amongst non-autistics except perhaps for the sense of discrimination claimed by people who self-identify as “gourmets.”

**Health reasons.** Indigestion was also frequently mentioned as a reason to avoid eating meat by diagnosed participants (e.g., “Meats upset my digestion,” “[Beef and pork] make me sick (stomach pain, nausea),” “Digestion issues with [seafood, beef and pork]”). Though indigestion can be considered as a health reason to avoid eating meat, indigestion is more specific than health. Two participants avoided meat for a health reason that was not specified. Alex wrote in the survey, “I was first a vegan for five years but am now a vegetarian- and after years of adjustment I have realized how much meat and dairy negatively affect my health and overall well being.”

**Ethical reasons.** Several non-male autistic participants avoided eating meat for an ethical reason while a few other non-male participants specifically mentioned that they avoid eating
meat for reasons other than an ethical reason. A self-diagnosed participant answered that she avoids eating meat because she is “horrified by the suffering of animals, and by the fact most people don't give a second thought to it.” Some participants who used to avoid eating meat for an ethical reason were regretful that they now eat some meat again because of limited choices. Loren who once avoided eating meat for an ethical reason for two years as a child talked about their previous vegetarianism: “It was for ethical reasons around the treatment of animals when I was 11. I wish I could've kept it up, but the sheer number of food restrictions I had as a result of that and my other existing ones made it impossible.” Alex who was once vegan for an ethical reason now lamented for being “basically a bad vegan” due to limited choice of places to eat out:

I made the decision to be vegan overnight. The day before that night I went to a family party where it was a buffet style meal where the food stayed out for 4-5 hours and one just eats at a steady and constant rate. So I had the experience of eating many different types of chicken wings and the repetitive act of pulling meat off the bone forced me to acknowledge that I was eating muscle off of what used to be a moving and therefore living creature.[…] At this point I’m basically a bad vegan. My heart is set on veganism but I fall short a couple times a week.

Medical conditions. A few participants indicated that they have medical conditions that make eating difficult. In the survey, Loren specified that they has aversion to many foods including fruits, and does not eat nuts because of their medical condition called ectodermal dysplasia. One of the common symptoms of ectodermal dysplasia is underdevelopment of teeth. They has five teeth, all of which are molars. During the interview, I told them that many individuals with ectodermal dysplasia are more likely to have food aversions, according to the National Foundation of Ectodermal Dysplasia. They was not aware of that but said that “it makes
sense” because “tongue is doing a lot of work.” Lack of saliva due to underdeveloped salivary glands of individuals with ectodermal dysplasia can lead to abnormal dryness of the mouth and an altered sense of taste or smell, according to the National Organization for Rare Disorders. Hearing that many individuals with ectodermal dysplasia are allergic to various food sources and some are even allergic to fruits, they replied “Wow. So I end up being in the same boat as them (because I can't eat a lot of fruits, particularly in their raw form, for texture reasons).”

**Experiences of invisible food deserts due to food aversions.** A lack of variety of foods that are edible was an issue for many participants who had very limited diets for various reasons mentioned above. They shared their experience of invisible food deserts. Drew, who is a vegetarian, said that one of their former workplace cafeterias served only soup and sandwiches, and “there was nothing to eat.” All of the sandwiches had meat inside. The soup was too salty though they generally likes salty food. They often had to grab lots of crackers that were served together with the soup and ate the soup just to not become hungry. At least there was no limit on the number of crackers to take. When they was on a gluten-free diet, there was “absolutely nothing” they could eat there. The sandwich bread, crackers and soup, all had gluten. Now they is not on a gluten-free diet anymore and their current workplace cafeteria provides much more varieties of food, but they finds it horrible:

> Nothing is good. It is HORRIBLE, HORRIBLE! There is absolutely no choice. I stopped going there. I don't even talk about going there. While there are vegetarian versions of pizza, hamburger, even hot dog, there was no proper salad bar like those you see in many places.

They said many of their coworkers complain about the food choices regardless of whether they are a vegetarian or not. There is also no proper salad bar near the workplace. That means there is
no such place near their house either because they lives right next to it. When I asked if they thoroughly searched to see if there is any, they answered, “Searched. But not around here. If you want to eat bagels, you can find.” Tony also had difficulty finding places that served veggie food when he was on a vegetarian diet. He was on the diet because he recognized what foods cause constipation; avoiding them influenced his choice of place. Tofu is difficult for him to digest, so that eliminated many/most veggie meals. Once he began eating chicken regularly it was not difficult to find places to eat.

For some participants, at least one same edible food item being available was more important than having an abundance of choices or a constantly changing menu. Samantha has limited number of “safe foods” that she prefers for taste and quality, but her workplace cafeteria routinely changes menus without offering some staple foods she can eat. She complained, “The food at the cafeteria changes daily (no predictability new choice every day).[…] I would much prefer self serve and at least one item offered every day” For her, having that safe food was more important than having various kinds of food available. Her preference to eating the same food was echoed by many other participants. They said they are totally fine and actually prefer having the exactly same food every day. In the answer to the question on why they thinks they is autistic, Lydia included being “totally okay with eating literally *the exact same thing*24 for every meal.”

Tony cooked and ate oatmeal for breakfast virtually every day up until the time he retired.

An issue of food aversion in the context of social situations was raised by Daniel. They pointed out that social situations tend to revolve around food but oftentimes there was no edible food in the social gathering for people who have certain food aversions. They has aversion to hot

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24 These asterisk marks (*) are used by the participant possibly to emphasize the word, “the exact same thing.”
spicy food but one of their friend’s birthday was celebrated in a restaurant where every menu item was extremely spicy:

For a friend's birthday party, I went to a ramen place that had a gimmick: Eat the spiciest thing on the menu, including the broth, and get your photo on the wall. I figured I can just order something else, so I looked over the variable scale of heat on the menu and chose the item explicitly labeled "not spicy". It was like drinking straight hot sauce.

Maintaining a vegan/vegetarian diet also was challenging in the context of social situations. Alex stated that the most difficult part of being vegan was “social interaction, not intellectually but simply from the difficulty of where [she] could eat.” When she lived alone she often had cooking parties with her close friends, which solved the previous problem. She is now a “bad vegan” or vegetarian for the past couple of years and it has been a lot easier in terms of social engagement: “It’s a lot easier to find something vegetarian friendly to eat on a menu.”

Drew is a “flex-vegetarian,” but grew up in a culture being vegetarian is extremely difficult and was forced to eat meat in social situations: “If you don't socialize, it is easy being vegetarian.”

They had to eat at least very little amount of meat: “I eat like a mouse. […] I would only eat the best of the best. If it is not perfect, I don't even touch. I have my criteria. People agreed with my criteria.”

Several participants had aversion to touching foods with hands in addition to aversions to eating certain foods. When only foods that are commonly served without eating utensils were available while eating utensils or someone to help cutting the food were not, they could not eat the food. For that reason, even when prepared food is sitting in front of them on a plate they might feel like being in a food desert. Although there is food “there,” it is, in effect, inaccessible.
Sally reported that Rose does not like to touch foods with her hands but has difficulty using a fork and knife, and needs assistance with cutting:

Sometimes she will need assistance with cutting. If I am not seated next to her, she may just sit there and look at her sandwich and expect it to be cut up for her. Or the staff may not even deliver utensils with a sandwich or pizza for example because most people do eat these items with their hands. She doesn't have a means to ask for a knife and fork.

Some diagnosed participants, too, answered in the survey that she has difficulty using utensils: “Have trouble with using forks properly.” Alex has no issue with using a fork and knife, but has an issue when a fork and knife is not available. She would not eat food if she cannot eat it with a fork and knife. She does not eat the top bun of a burger because she eats everything with a fork and knife and it is too complicated to eat a burger with the extra bun on top. Usually her choice of food is “dictated by the fact if [she] can eat it with a fork and knife or not.” If a desired option is not available she usually prefers to not eat. Even sometimes when she goes a vegetarian restaurant and has the whole menu at her disposal, she still only eats one or two things. Drew does not eat a pizza slice without a fork and knife unless they is extremely hungry, although pizza is their most favorite food. They does not like to touch food with their hands and does not eat finger foods. Another issue with foods that are served without a fork and knife was that biting a big piece of food in front of others can be disgusting. Abby mentioned:

I don't feel comfortable biting food in front of others. Eating a salad or small pasta is okay, but I feel disgusting biting into something big, like a pizza slice or a sandwich (another reason why I don't like sandwiches!).

Invisible food deserts due to food aversion were experienced in grocery stores as well as in eating places. Loren, who has strong food aversion, said that it can be annoying when they
cannot find items such as a specific type of sauce or noodle “given how there's very few things [they] make on a regular basis.” *Their* main foods include pasta, chicken tikka masala with rice, udon soup, noodle stir fry, mac and cheese, pasta and bean soup, tacos.

**‘Unsafe’ people who enforce unwanted diets or social interactions.** The concept of ‘unsafe’ people first emerged as I encountered a survey participant’s response, “I only eat out with people who are safe or at least semi-safe people for me,” and Loren’s experience of discrimination due to *their* food aversions and objection to certain diets being imposed upon someone. It seemed that ‘unsafe’ people may be those who do not understand autistic people’s real challenges such as food aversions and overwhelming social interactions and pressure them. Loren expressed *their* wish to be understood and not to be pressured by people, when asked to make a comment at the end of the survey:

The main thing is, I'd really like to see people take food aversions and executive functioning issues seriously and not think that they're something we choose to experience. If more people realized that we're trying our best and didn't pressure us to eat in certain ways, I think we'd be better off.

During the interview, Loren shared *their* experiences in detail. *Their* aversion to various common foods was a challenge when *they* eats with others because *they* needs to make special orders:

I have to special order pretty much everything. Sometimes it's just "no cheese on top."

And other times it's specifying that I need it without some common ingredients. E.g., hamburgers have to be made with just the meat and the bun, because all the other textures are not doable. [Like tomatoes and lettuce].

When *they* dines out with others, *they* tells other people about *their* preference, but *they* also “gets nervous” about doing so, because *they* expects people to “react badly.” Now that *they* is an
adult, people generally react “pretty well,” but when they was a child, many people said that they was spoiled and too picky, and accused them of “making it up,” and put “shame” on them for their food aversion. While talking about the notion on certain diets for autism, they raised an issue of imposing certain diet to others and shaming them if they do not follow: “I figure people can do what they want with their own bodies as long as they don't impose it on anyone else or shame other people for not following it.” When asked if people made them feel shamed because of their food aversion, they replied, “Oh yeah. A teacher hauled me up in front of the class once to yell at me for not eating the cheese on my pizza. Because it was "wasteful." Even though it would've made me puke.” Discrimination against their food aversion still continues: “Thankfully the last really bad situation was in 2012, where someone at a job interview insisted on taking me to a restaurant that I said that I was really not confident about my ability to eat at.” While a job interview over a meal is a chance to test a candidate, it is also a chance for a candidate to see if the match between them is good. When I reminded her of this aspect, Loren added, “That was a red flag. That entire interview was a giant clusterfuck. I could've sued for discrimination.” It was disappointing that the organization that discriminated against them for food aversion was a nonprofit disability rights organization. They lamented, “Which makes it all the worse.” They was in enough shock that they barely spoke for the rest of the day.

In some social situations, even friends unintentionally enforced unwanted food. Talking about their experience in one of their friends’ birthday party where there was no edible food for them, Daniel addressed that most people “don't CONSIDER that [they] might not be able to eat anything depending on where they go as a group.”

Unwanted social interactions that are enforced by ‘unsafe’ people were abhorred by several participants. Their frustration was expressed in their all capitalized phrases or sentences
in email interview responses. When asked about challenges eating out, a survey participant checked the ‘Other’ option and specified, “Coworkers trying to talk to me during my BREAK FROM WORK.” I heard the same crying out against unwanted social interaction from Alyssa. When asked to try to remember a recent time when they were very annoyed by some aspects of eating out, they complained about many people who tried to initiate social interaction that they did not want: “TOO MANY PEOPLE. I DO NOT WANT TO TALK TO THE PEOPLE. THEY DO NOT UNDERSTAND THAT I DO NOT WANT TO TALK TO THEM.” Their aversion to social interaction while eating out seemed to be partly related to difficulty having conversations during mealtime: a diagnosed participant described the difficulty as “Juggling conversation and eating.” Samantha too revealed how much she hates mealtime social interaction at the workplace cafeteria and likes using vending machines for her meals. When asked about how her workplaces were good or not good at "feeding" their "aspie" employees, she said:

[In NASA and another company] there were vending machines where you could get breakfast, lunch and dinner restocked regularly so I could count on the same thing every day. At vending machines you don't have to wait in line, experience the horror of social chit chat [emphasis added] or the chaos of a cafeteria.

While other participants often talked about the chaos of a cafeteria in terms of crowding and noise, Samantha had an issue with a chaotic aspect of social interaction:

It is not the room that bothers me but the purpose to encourage social bonding which I know I must practice for team cohesion and advancement. This is the discomfort. It is something I find hard but in industry one must do it and even seem to enjoy it.

Drew also mentioned that they does not like going their workplace cafeteria because of unwanted social interaction there. While “the real reason” why they does not like eating there was because
of feeling greasy while eating and indigestion after eating there, encountering people who would recognize them was another reason they does not like eating there. They doesn’t like “those small talkers,” who “don’t know how to make silence.” They “would just disappear when a small talker approaches” but that is not easy when eating.

Unwanted social interactions were enforced while shopping for grocery as well. Alyssa finds it very annoying when people keep trying to ask them if they could help. They just needs them to leave them alone so they could shop properly:

Adding even one person I'm supposed to be interacting with and calculating for is enough extra that I will wind up on autopilot in the grocery store, which is a problem because I can't actually make decisions based on what I want when I'm on autopilot.

A self-diagnosed participant identified staff who promote food products as a source of challenge. Although encountering unwanted social interactions was a huge issue to many participants, they were fine with social interactions with friendly but not intrusive people. Some parent participants even considered friendly staff as one of rare positive aspects of some food places. Both Hannah and Sally stated their children’s favorite places have friendly staff who know their children. Jason likes to eat at PDQ, a fast food restaurant, for its friendly staff who give positive attention to him as well as its chicken tenders. She said, “There is positive reinforcement there because the staff all know him and say hello. He likes that they only do that with him and no one else. He enjoys positive attention.” Regarding friendly staff, Sally noted the importance of smaller, local-type places for Rose:

I think the people working there can make a huge difference in places she likes to go.

[…] She also likes a smaller place where she knows her way around. Of course
familiarity, casualness and a non-chaotic environment really help. She likes local-type places where the staff know her and welcome her.

Unlike many other participants, Rose is somewhat social and does enjoy it when waiters “chit chat” with her and pay attention to her in a fun way. Sally emphasized the importance of staff’s efforts to directly communicate Rose: “It's nice when the wait staff actually direct their questions to her personally (especially for yes/no questions) instead of ignoring her and going straight to asking me.”

**Prevalence of over-stimulating food places.** Autistic participants tended to “go hungry” if leaving over-stimulating food places is impossible rather than eating there. For example, when asked about how *they* deals with an uncomfortable environment to seek out comfort, Alyssa replied, “If I was on my own, I left and was hungry instead. With family members who don't get it, I tend to go on autopilot, which isn't actually good for me. […]” In this section, I will detail the following aspects of over-stimulating food places: crowding, noise, lighting, odor and store layout.

**Crowding.** Crowding is perceived by a person when restrictive aspects of limited space are experienced (Stokols, 1972). The level of crowding is experienced differently depending on individual differences and situational factors. While personality, gender, and culture are commonly considered individual-difference variables that relate to perceiving crowding, being autistic also seemed to be a potent individual-difference variable. The levels of crowding experienced by many participants were very high. As a reason to consider *themself* to be on the autism spectrum, Lydia wrote, “Absolutely hate crowds and crowded locations because they're overwhelming and drain me of energy to start, do, or finish things, or just to concentrate, or just to survive.” Mastermind once said, “A place like Jackson Heights is death sentence to people
who are autistic,” because of its crowding, though he had had a great time\textsuperscript{25} when we all gathered together for a dinner there. Hannah said Jason has difficulty eating out because of two reasons, one of which is crowding, while the other is noise. Eating out was too much stimulation for him and he did not like to get too close to people because he does not like to be touched. He has a complete meltdown if they go anywhere other than where he wants to go, and if there is some place crowded “he simply won’t stay and it’s time to go home.” Many interview participants found that crowding in a grocery store is challenging. Alyssa does not like crowded places because “the need to deal with people tends to land [them] on autopilot.”

\textit{Noise.} Noise is unwanted sound. According to Bilotta and Evans (2010), “the psychological components of sound (e.g., unwanted) and its physical components (e.g., intensity) play a central role in perceiving noise” (p. 30). Many responses regarding noise were related to psychological components of sound. Hannah said that Jason is particularly overwhelmed by the sound of many people talking at the same time when eating out and “It isn't volume as much as it is the clatter of different people talking all at the same time.” While there were several sources of noise in grocery stores (e.g., background music, noise from customers talking and pushing their carts, and employees promoting items), background music was frequently mentioned with regard to its unwanted psychological effects. Though noise was not a huge issue for Tony because he “simply avoids noisy stores,” he talked about how he is annoyed by Christmas music: “I just hate Christmas music in the stores, you can't even turn it off.” He hates it because much of it is “sappy” and he doesn't want to “be dictated as to having to 'get in the mood.'” He wondered how checkers in a grocery store were “dealing with it.” Drew also does not like Christmas music that

\begin{footnotesize}
\footnote{\textsuperscript{25}He had a great time there possibly because he paid more attention to our gathering and less attention to the environment of the place. Some autistic adults in this study also felt less stressed when they paid attention to a close person. Another possibility is that he had a great time because we hung out from evening to night, which he later told me as a more comfortable time for him to go out due to less light and less crowding.}
\end{footnotesize}
is “repeated over and over again,” because it tries to create the Christmas mood. They tend to become depressed and frustrated during the Christmas holiday season because that is the end of the year but they “did nothing” during the year. Christmas music in a grocery store only exacerbated that feeling because of the Christmas mood it insists upon. They said they empathizes with The Grinch, a character in a Christmas story, *How the Grinch Stole Christmas!*, who hates holiday spirit. As a sensory challenge, a diagnosed participant too identified background music of grocery stores; she wrote “muzac.”

The high intensity of sound also was problematic to many participants. Daniel’s least favorite places to eat out were the vast majority of bars largely for its noise: “They are too loud to appreciate the space much less have a conversation, and thanks to the emphasis on liquor, the food selection is a lackluster afterthought.” Loren does not go to bars “because it is almost guaranteed to be loud and crowded.” Another diagnosed participant specified “screaming babies” as a source of noise that makes it difficult for her to comfortably shop in a grocery store.

**Lighting.** Dim lighting was generally preferred by participants, but many places, especially low-end places, have bright fluorescent lights, which cause headaches for many of them; Lydia mentioned that they is physically hurt by a lot of fluorescent lights. Alex said, “I do not like when it is terribly bright.” Fluorescent lighting in a grocery was a huge problem to many participants. Even though dealing with fluorescent lighting alone might be manageable, there were other sources of annoyances in the store. When these issues are combined, autistic individuals can be very annoyed. When asked about the moments when they was most annoyed while shopping for groceries, Alyssa talked about the issue: “There was fluorescent lighting that was giving me a headache, and there were people who kept trying to ask me if they could help

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26 Muzak is a major supplier of business background music.
and I just needed them to leave me alone so I could shop properly.” As mentioned above, Abby likes to shop for groceries, “but just hated the fluorescent lights.”

**Odor.** Drew and Mastermind, who are sensitive to odor like many autistics, shared their issues with smells in food places. Drew hates their workplace cafeteria partly because of its smell, which they related to air quality:

[The cafeteria] is too greasy, everything. You go and sit in front of a kitchen. That's the feeling. At least that place doesn't have stinky drain. Another place I worked had stinky drain, sewage smell combined with greasiness. That was absolutely the worst place to eat. I had to eat there every other day.

When asked if they thinks the place is extremely greasy or smelly to everybody or they thinks they is more sensitive to greasiness than other people, they answered,

Maybe I'm more sensitive to the greasy smell. For example, when I fry eggs, I always put the used pan outside of the house. I know many other people don't do that. But I think even you'll also smell that sewerage smell very strongly.

Drew also hates the smells from a seafood counter and does not go near it. They was particularly disgusted by the smells from seafood that is sold without glassed showcases in some Chinese or Korean stores in New York. Mastermind finds smell from halal meat stores disgusting. Once he experienced disgust, while his father shops there, he never entered those stores again.

**Store layout.** Store layout that is easy to navigate seemed to be particularly important to autistic individuals, many of whom find social interactions difficult or overwhelming, because one would not need to bother interacting with staff in a store with an easy layout. While answering their most favorite grocery store, Alyssa said:
Next on the list would be “any grocery store that I have learned the layout of and can get to either alone or with the help of someone who can understand and accept that they need to stay away from me while I shop.”

However, many grocery stores had inconvenient and confusing layouts. Oftentimes participants explained about store layout of their least favorite grocery stores. For example, Union Square and the Houston locations of Whole Foods are Alex’s least favorite grocery stores for their store layouts. She feels specifically the layout of the Houston location is problematic:

It has an entrance where one literally has to walk through the on coming traffic of the cashier line. Very daunting. They are also just very large with lots of people constantly. But also, the Houston location has a very peculiar set up. The building is more of a horizontal long rectangle with the aisles moving in a perpendicular fashion. Although it has the quality that she likes, she still prefers not shopping there. Daniel finds it annoying to shop in a grocery store with a confusing layout: “There is one Trader Joe's in my area with no section labels and such an odd layout that it feels as if the products are intentionally hidden to prevent people from buying them.” Their least favorite grocery store is Costco because its “big size plus layout come together to encourage getting lost inside the store.” Rose had a difficult time when her Food Coop moved to a different building because everything was arranged differently. Sally said “It took her a couple months to get used to it, but she figured it out.”

**Hours of operation experienced as restricted.** Many interview participants’ responses implied that autistic adults have increased needs to access to food at off-peak hour, which may make them experience hours of operation of food places as restricted. Noteworthy reasons for
such needs include delayed awareness of becoming hungry, preference to work at late night and avoidance of peak hours.

**Delayed awareness of becoming hungry.** Many participants had an issue of not being aware of becoming hungry and suddenly feeling hungry when it is too late to easily access food. Hannah’s son, Jason, is one example:

[My son] eats whenever he is hungry and demands food when he's ready (not necessarily when anyone else is ready to eat). He does not give any forewarning, just finally says I'm hungry and we take him to eat. If you try to feed him on a schedule he will simply choose not to eat and will be agitated.

Many autistic participants had to rely on their executive functioning to make sure they eat even when they do not feel hungry, because sense of hunger can come suddenly. But, they often had problems with their executive functioning. When Alyssa frequently forgets to eat, *they* becomes concerned about *their* executive functioning because forgetting to eat is a sign of *their* executive functioning “being shit again.”

Not being aware of becoming hungry and suddenly feeling hungry on top of having issues with executive functions would be also problematic regarding grocery shopping time if one suddenly becomes too hungry while there is no easily accessible food and grocery stores are closed. When asked what time they typically go grocery shopping and their reasons, many answered that they go when they become hungry. Alyssa said, “When I get hungry and there's nothing I want to eat because that's when I remember that I need to. This is not a good system.” Loren echoed the same story: “Whenever I get to the point of there are no more meals in my house and I can't justify spending any more money eating out.” *They* explained that, because of *their* issue with executive functioning, “[to] get the momentum to do a thing, even a thing [*they]*
want[s] or really [has] to do, can take a lot of time and effort.” Sometimes their “stomach has to be really hurting badly” to get them moving to make or buy food. Though Drew goes grocery shopping other than when they feels hungry as well, oftentimes they goes when they has nothing to eat at home and feels too hungry. They takes two spoons of honey before going grocery shopping to prevent feeling too hungry while shopping for groceries: “When I feel hungry, it is inconvenient because I can’t make a right decision, and I only buy sweet food and no real food.” Loren echoed Drew’s response: “When I get to that point, sometimes my partner has to tell me what to buy, make or order because I can't make a decision.”

Preference to working at late night. For Drew, who works until late night in a suburban area, hours of operation was an important issue when eating out. They often worked at night in their office after their officemate and other coworkers went home because they thinks more clearly at night and there is nobody to distract them. The only issue regarding working late at night was that there was no place to eat. The cafeteria of their previous workplace closed in the early afternoon. The workplace was located in a huge campus in a suburban area and they “dreaded” leaving for restaurants outside the campus that were sparsely located. Drew felt they was completely “trapped” inside of their workplace at night. They often ended up skipping dinner to avoid “wasting time just doing back and forth” and ate any available “junk food” from the vending machines in the workplace “just to kill hunger.” Having a 24-hour cafeteria that serves some edible food has been their dream. Their situation was contrary to Samantha’s. Her workplace has a 24-hour cafeteria even though she avoids going there to avoid unwanted social interaction. Like Samantha, Alyssa, a graduate student, has access to a cafeteria that opens 24 hours a day. The cafeteria is for engineering students and has flexible policies on taking out food as well as hours of operation:
My meal plan is specific to the International Engineering Program (IEP) House and Texas Instruments (TI) House, two renovated frat houses that are run by the IEP. The dining hall is in the basement of the TI house, and that's pretty much the place where I can get food from my meal plan. Unlike the main university meal plan, I can get into the dining area 24 hours a day, 7 days a week, though the times when hot meals are out are limited, so there's more flexibility in when I can get food. I'm also able to bring food out of the dining room, which is different from the main campus meal plan.

Drew presently lives in another suburb and it makes it difficult to find eating places that are open late. They often ends up eating at Chipotle that they “hates so much,” because there is no other options. When asked why they eats there while hating it so much, they answered:

I don’t know. That's me. Because it is the best restaurant in the town. But you know the best doesn't mean it is good. Ok, let's talk about the competition. I go there when my rice is not ready. Among the places that are open after 9pm, there is Wawa, a sandwich place.

I don't like the environment there. They don't have seating.

They considers that Hummus, a Mediterranean restaurant, is the best among places that are open until 9 pm. They likes the place because, with the same money for a burrito at Chipotle, they can eat a proper Mediterranean meal. After eating a salmon dish in the place, they does not become hungry quickly. When they eats a vegetarian burrito at Chipotle, which does not serve any fish dish, they becomes hungry soon. They wants to have a “proper” eatery like the Mediterranean restaurant or a buffet-style restaurant that opens until late night near their place.

Avoidance of peak hours. Another reason why hours of operation may be experienced as restricted is because participants eat at odd times to avoid sensory challenges and unwanted social interaction during regular hours. Drew usually shops at late night to avoid crowd, but most
stores in their neighborhood closes early. They often ends up buying in stores that are expensive, because stores open until late usually charge more. This leads to the section on exacerbating factors that includes limited financial resources.

**Exacerbating Factors**

Negative experiences of invisible food deserts were often exacerbated by (a) limited financial resources, (b) difficulty in asking for changes or help, (c) limited mobility due to lack of driving skill, and (d) challenges in cooking and growing food. Below, I will illustrate these exacerbating factors and discuss their interplay with invisible food deserts.

**Limited financial resources.** Many diagnosed participants were low-income and/or students, and price was a factor in limiting the choices of foods and food places to them. For those who have food aversion, which limits the choices of foods, the adverse effects of the limited financial resources on food access seemed to be particularly strong. For example, Abby, who already had serious food aversions, also had financial strain, which prohibited her from trying healthy food or even having regular meals:

If I had a better financial situation, I would definitely experiment with diets. […]

Unfortunately I am working a minimum wage job on a part-time basis, so this doesn't easily allow me to purchase supplements, buy organic foods, increase my protein levels, or even eat regular meals. I oftentimes skip breakfast and/or lunch, and undoubtedly this impacts the presentation of my difficulties. I become more anxious when I am hungry, am prone to disassociate, and my clumsiness/cognitive issues are exacerbated. It is a vicious cycle because lack of food can contribute to my employment issues and my irregular employment can contribute to my lack of food.
One the other hand, affordability of eating-out places is directly related to variety of food. Daniel explained how their budget and time compelled them to eat at a place with limited choices:

Currently my most frequent food stop is the dollar store across the street from where I work, where I usually get frozen burgers. The compelling circumstance is that I need something cheap and fast during my lunch break. My main complaint is that the one-dollar restriction apparently affects both amount and quality. I would be fine with spending more than a dollar to get high-quality food in several small packages, but that option is not available.

The low-end also often entailed over-stimulating environments such as too bright lighting and crowding. For example, Drew is very frugal and sometimes wants to eat just a piece of cheap pizza; but those that sell cheap pizzas are usually too brightly lit with many fluorescent lights and they finds entering into such store very off-putting. It is significantly disturbing eating it there. At the same time, they “run[s] away from restaurants with candle lights” because they can imagine the high price, even though they prefers dimly lighted restaurants: “Things that I like are all too expensive…” They thinks some “cheap places” intentionally have bright lights “not to scare people like [him],” who are “cheap.” For Drew, who is sensitive to too bright lights and has quite limited financial resources, options of restaurants were very limited.

Daniel’s favorite place to eat out is Olive Garden for its soft ambient environment without much crowding as well as food selection that pleases their taste, which is their “most delicate sense” but their limited financial resources discourages accessing the place:

Their main reason is the actual food selection, since taste is my most delicate sense. In addition, most Olive Garden locations feature dim lighting and soft music. They also
seem to have not too many people at once, as long as it's not Valentine's Day.

Unfortunately the price tag on Olive Garden prohibits me from visiting more often.

While aesthetic quality of places may alleviate stress that is caused by environmental stressors such as noise and crowding, low-income participants seemed to be also more likely to eat at places of lower aesthetic quality. Among ten diagnosed participants who checked the aesthetic quality of eating places as a challenge when eating out, all but one were low income. Unfortunately, almost all of them did not participate in the interview phase, and I could not ask them further about how aesthetic quality of eating places make it difficult for them to comfortably eat out. I had to ask Drew, who did not check aesthetic quality, about aesthetic quality of their eating places, remembering that they found their former workplace cafeteria extremely depressive. Because the company laid off many employees over recent years, only a small corner of the huge space was lit. They felt it was symbolizing the “doomed” and “collapsing” company. Back in the day the company was one of the most innovative and successful companies but now it was barely surviving by selling properties and laying off employees. Dining tables and chairs were old-fashioned and worn out. The color of the place looked very dull and flat. At least natural colors of fresh fruits and vegetables could have added some lively colors to the “dead place” but no food was displayed there because the only foods the place served were sandwiches and premade soup. When they once visited my school cafeteria at the CUNY Graduate Center, they was very impressed by the naturally lit space with skylight as well as by a colorful artwork and beautifully displayed affordable high quality food. They did not check aesthetic quality of eating places as one of the answer choices because they felt noise, lighting, air quality and hours of operation were more critical. Nevertheless, their detailed description of the depressive cafeteria despite its relatively low perceived importance, along with
the large number of low-income diagnosed participants who found aesthetic quality of eating places challenging, implies that the issue of the aesthetic quality of low-end eating places needs more attention given its potential to reduce stress.

Although low-end places tend to have more environmental stressors such as fluorescent lighting, it is also important to note that higher-end places are not necessarily without stressors. Samantha, who is one of few high-income participants, shared her struggles with some higher-end places. Her least favorite eating out place is Olive Garden for its artificial aspects—from ventilation, servers, and a digital bill payment method:

There is a semi industrial feel and smell to their restaurants. The air flow is irritating almost like they have deliberate positive ventilation of cool air. The waiters are overly intrusive as if they are auditioning to be my next friend and then to top it all off once you have ordered and gotten food etc. the check comes up on this impersonal iPad like device and you pay it via credit card. The juxtaposition of intrusive smells, people, airflow and background noise followed by the total disappearance of your new friend/waiter and the ipadish thing is bad.

She also, “…abhor[s] fancy work dinners which are usually continental and everything is touching with drizzles and god only knows what it really is.” When traveling for business, she would find a small kiosk, which does not require any social interaction, and eat in her hotel room whenever possible. For her, the easiest places to eat out have “non-industrial, non-reflective environment27 and simple food.” Alex echoed Samantha’s negative emotion toward too impersonal and artificial places; she considers some places are “so sterile and corporate.” Abby too likes “the personal touch” of small place, and particularly loves food trucks:

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27 An environment that does not reflect too much light or sound
I love food trucks! The personal touch is great. Food truck owners are always so much more accommodating and friendly than corporate restauranteurs. They tend to be more inventive with their offerings, and I love learning their stories.

**Difficulty in asking for changes or help.** Many participants mentioned that they often leave instead of asking for changes when they feel uncomfortable eating out. For example, Daniel said, “My main strategy is avoidance, so if the environment takes a bad turn, I will just leave.” The limited options of places in the ‘food deserts’ were further narrowed down. The reasons they would rather leave instead of asking for changes were mainly because they are “bad at” asking for things, become more stressed or drained while trying to ask for a change, and/or have no hope that there can be a change. Asking for a change is difficulty to Rose because she is non-verbal. Alyssa also said they is bad at asking for things: “Asking other people to change an environment involves asking for things, which I'm bad at, so I tend not to do that.” Samantha said she would rather do various things to change her own mind because trying to change the situation is only going to make her mad.

Drew does not ask for a change because they usually has no hope that a bad environment, such as the greasy cafeteria, can be changed:

I don't seek out. I just follow. I'm not a fighter. Big mouth people are fighters. Those who like bragging about things are fighters. You complain about something when you think the other side doesn't know what is going on. I think greasiness of the cafeteria is very obvious to anybody. I complain only if I have any hope. I complain only when I have attachment to something.

Even though greasiness of the cafeteria might not be obvious to other people, it seemed that they did not realize such possibility until I reminded them of it.
Drew also feels too drained after complaining about anything to someone:

You already don’t like interacting with people. And, now you have to talk about something negative. The interaction would become so negative. That is too much. I would feel so drained, completely exhausted. If you just suffer the bad environment for a while, in 99%, the situation will be naturally resolved. You leave the place. If you complain? You become depleted and ruin the rest of your day. You cannot do anything anymore that day.

When asked what they thinks about autistic people’s meltdowns in the context of their tendency of not asking for help, they answered that they thinks they have meltdowns “with a chance of meteorite hitting earth.” I probed if that means they thinks in most cases autistic people just bear the bad environment or situation without complaining, and that meltdowns happen only rarely. They said, “Yes, at least that’s my case. That’s when mostly my body is complaining.” They further explained “body complaining” while disagreeing with a notion that autistic people are more self-centered:

While the literal meaning of 'self-centered' is clear, the practical meaning of self-centered is very relative. Everybody is self-interested because if not, the body will complain very loud. The people whose body does not complain so loud can be calculatedly non-self-centered in order to have a larger benefit in the future. But in the end everybody has a body that complains louder than the world around (except in extreme cases). The kind of issues that make different people uncomfortable (body complaining) will vary from person to person.

28 General ‘you’
On the other hand, some participants did not ask for changes when they felt uncomfortable dining out with others, because they did not want to bother their rare dining companions. Tony usually eats alone when eating out because he is “unable to initiate or respond to social cues” and does not have many friends to eat together. He also has moderate prosopagnosia, a face blindness. That was “a big issue” for him because “it is difficult to build on the last interaction if one does not recognize the individual again.” He said, “Friends are found serendipitously.” Even those rarely found friends were usually someone he met in a classroom or at work. He was once “cut up” by one of his friends for asking a cleaning staff member to stop making noise in a restaurant:

I do recall a time in the 70’s I was dining with a couple friends. A cleaning staff member was operating a vacuum cleaner behind me; the noise was unwelcome. I’d asked politely that he stop; he did but seemed to be surprised. One of my friends later cut me up because I’d done so.

He is now by himself and he does not eat out with whom he does not want to eat together. Instead of asking for changes, Alex drastically changes her posture and style of sitting when she feels uncomfortable eating with others. She asks herself to take postures of a person who feels comfortable.

**Limited mobility due to lack of driving skill.** The ability to drive a car leads to increased mobility and independence. However, many young diagnosed participants did not have a driver’s license because they had difficulty in driving, which resulted in limited mobility and access to acceptable or favorite places. In a suburban area, grocery stores are not within walking distance. Because of the location, those participants who did not have a driver’s license had to rely on others for a ride. Public transportation is not convenient to use unless one lives near the
bus route. Even in urban areas, where most of the participants lived, limited mobility due to lack of driving skills limited access to favorite food places, which are rare. For example, Alyssa cannot easily go to their favorite restaurants for that reason:

I really like Moe's and I really like the wraps place that's at the top of my campus. I also like Minerva's, an Indian restaurant. All of these places have spicy food (yay!). Minerva's is generally fairly quiet, and I can take my food and eat elsewhere pretty easily from the other two. As long as I time things correctly (eat at an odd hour) I don't need to wait long for my food at these places. Getting to Minerva's or Moe's is a bit harder for me because those are car rides away and I don't have a license yet, which means I can only go there with somebody else.

For Mastermind, too, limited access to favorite grocery stores due to lack of mobility was an issue. He “hates” going grocery and does not go, but he said he would be able to go grocery shopping if there was a good grocery store near his home. He liked a supermarket he visited on the way to his aunt who lives far away. He took some photos of the supermarket, and showed them to me comparing them to a photo of an ethnic store his father frequents. The grocery store he visited during the trip was very spacious, had soft lights, had walls painted with a gentle monochromatic scheme and looked lively with fresh fruits and vegetables. On the other hand, the ethnic store was very small, cluttered, too brightly lit with fluorescent lightings, and there was no order in the color scheme. He said he wants to get a driver’s license soon, but was concerned about his motor skills that might make driving difficult.

Some participants shared specific challenges with driving and learning how to drive.

Abby’s doctor suggested she stop driving due to panic attacks:
When I drove (before my doctors told me that it wasn't a good idea due to panic attacks in intersections), I did like to shop. I just hated the fluorescent lights and the physical part about shopping (I'd always drop things and make a fool out of myself). I go grocery shopping, but only with family members who can drive (so I don't have much control over where or when I shop, and I don't go to the store that much anymore).

Loren did not drive until a year ago because they had difficulty learning previously: “I tried and was easily stressed out by all the things I had to keep track of.” They worked with an occupational therapist last year who helped them learn how to drive a car with an automatic transmission. They said going grocery is much easier now that they can drive. Drew has been driving since their early 20s and is very skilled in driving, but they has difficulty driving unfamiliar places at night because they has mild nyctalopia and cannot see street signs well at night in dark places. They is also often confused between left and right when driving and has to pay much attention: “I always have to think which side is left and which side is right, just like I have to think to give an answer to something like the square root of 196.”

Although driving skill contributes to enhanced mobility and easier access to food places, it is important to note that the food environment with more food places within walking distance is more desirable. Though Drew drives, they finds driving to go grocery shopping is a “mental block” when they is not psychologically ready for grocery shopping. They misses the time where they lived near a farmer’s market:

When I lived in a place right next to a farmer's market, I went there even during the day time, 5 pm. I always bought at 5 pm because it was cheap when it closes. I would go even without changing clothes. But now, I go even to Whole Foods by driving...It is a mental block. I cannot go in flip flop.
Challenges in cooking. Home is where one has control over privacy, which translates to reduced sensory challenges and social interactions. When asked about their favorite place to eat out, Daniel’s answer started with the following: “My favorite place to eat tends to be at home, since it has the best sensory environment. For ‘eating out,’ my first choice is […]” Drew said they is a type of a person who would never eat out if there is prepared food at home. Samantha likes eating “at home in front of the fire place or at the dining room table or on the deck in the spring, summer, and fall.” For people who find eating out daunting due to challenges described in a previous section, eating at home more frequently by cooking could have been an alternative. Some participants actually had some or special cooking skills. For example, when I visited Drew, who “do[es] not cook,” they made a huge pot of lentil soup with turmeric powder, carrots, frozen kale, ginger, cinnamon sticks and some salt. I was very surprised by how tasty the soup was. Their delicate sense of taste seemed to have helped them cook that delicious soup. They said that they can tell how the food is going to taste by just smelling the air where food is being cooked.

However, many autistic participants, including Drew, had challenges both with eating out in and cooking. In this section, I will focus on reporting findings on challenges in cooking, which I consider a factor that lead autistic people to more frequently eat out than desired in invisible food deserts. Before that, I will first report what cooking meant to interview participants, which showed a wide range of definitions of cooking and little excitement about cooking. Then, I will report survey results on challenges in cooking. Lastly, I will discuss the following areas of challenges related to cooking: executive functioning, lack of energy, dangers while cooking and lack of an adequate place in which to cook.
Meaning of cooking. Meaning of cooking varied among participants. I knew Drew regularly cooks rice and sometimes cooks kale and eggs. But, when I asked if they cooks, for a pilot interview, they said they does not cook. They has a very clear idea of what cooking means, and thinks they does not cook, based on that definition. For them, cooking is almost impossible because they thinks about food only when they feels hungry, but when they is hungry they cannot cook because cooking requires planning and much efforts:

Cooking, for me, is equivalent to being difficult. Cooking means combining all kinds of ingredients. Cooking involves cutting, baking, dicing, grating, peeling. It has to hurt hands. It is work. It is starting from scratch. I don't cook because cooking needs lots of planning. You can't cook when you're hungry. Cooking is work. Work tires you. What's surprising if you feel tired after you work? [...] Cooking is the work that is omitted in TV cooking shows. No washing dishes, no cutting all the ingredients, no waiting. In a TV cooking show, it says 2 hours later, and then “Ta-da!” The food is ready.

Tony’s definition of cooking is much broader than Drew’s. He defined cooking as “any food preparation, including preparing a salad, building a sandwich, microwaving prepared foods such as from a can or microwavable pouch; might as well include running the espresso-machine.” He currently cooks about 2-3 hours per week because he does not like “the hassle to cook” just for himself. But up till the time he retired, he cooked and ate oatmeal for breakfast and cooked dinner virtually every day. Currently, if he prepares dinner, “it will be something out of a pouch and/or possibly only have a salad, cook boneless, skinless chicken breast simmered for an hour or so, whole potatoes, fresh carrots or frozen peas, often as a soup.” He is also partial to the powdered gravy mixes. He will use the liquid left from cooking the chicken. His philosophy on food is influenced by his mother: “My mom's formula for dinner was meat, potato and a
vegetable; […] and we always ate well, not anything fancy, just wholesome food. Pasta and rice were only occasionally served, same as I do now.” Alex defined cooking as making a meal from near scratch. She uses canned beans or frozen hash browns, but always cooks with fresh vegetables. She mostly makes her own broths, but sometimes uses vegetable broth if a recipe is demanding or gives emphasis in other areas. She usually cooks breakfast in 30 minutes every day and dinner 4-5 nights a week for approximately an hour. Alyssa and Daniel do not consider microwaving premade food as cooking, but their definition of cooking is quite broad. For Alyssa, even “[adding] boiling water to something and then microwaving it” is cooking. Daniel defined cooking as “preparing food with at least some possibility of artistic freedom.” Though they usually does not prepare food, they most often cooks for potluck events. Their usual potluck dish is macaroni and cheese, “sometimes with pesto sauce in the cheese mix to put a personal spin on a classic.” They cooks macaroni because it is “reasonably simple and easy, while also being something that clearly required effort, thus avoiding possible social stigma associated with bringing, say, a bag of chips instead.” Loren defined cooking as making their own food. Their cooking involves washing, cutting, stirring, using fire, and adding spices. They cooks that way most nights. Samantha defines cooking as “opening boxes, adding stuff, warming or heating until rehydrated or coagulated or a reasonable temp and texture.”

While the autistic interview participants generally did not show any excitement about what cooking means to them, Rose’s mother, Sally, shared her and her daughter’s love for cooking:

Cooking is a super way to connect! There is so much to do and so many opportunities for communication and choice-making and skill-building, as well as some great sensory opportunities and learning ingredients and measurements. Looking through recipe books
together to determine what she would like to make, deciding what ingredients are needed, shopping and the actual cooking are all great ways to interact. One of our favorite ways to spend a Saturday when there is no work or program is to: wake up and cook a wonderful breakfast, clean up our kitchen, go out for a long hike, come home, shower and cook up a fantastic dinner!! This is NOT fast food! The breakfast process takes about 1-1/2 hours and the dinner, at least 2 hours. She knows when it is a Saturday since she gets to sleep in. The first thing she does when she gets up is sign to me that she wants to "chop". Her usual weekend breakfast involves sweet potatoes. This is quite a ritual. I probably shouldn't call it "her usual", more like "for sure"! Saturday morning is sweet potato pecan pancakes and Sunday morning is a sweet potato/sausage/veggie fry-up. That routine is pretty standard. There are lots of ways we interact while cooking. She can physically do a lot of the tasks, but needs direction as far as what ingredients, measurements and how to do things. We also take our time and smell ingredients (the pancakes involve 5 different spices which all get smelled as well as the vanilla). She also actually likes to clean up the kitchen afterwards too! She is very tidy and wipes all surfaces and washes the dishes in a dishwasher. We are very lucky to have this time and individual attention luxury. I don't see how they could do this in a communal residential living arrangement.

**Challenges in cooking.** The survey results show that ‘Time Constraints’ was most frequently chosen as a challenge for cooking (12 diagnosed participants; three six self-diagnosed participants). Seven diagnosed participants and two self-diagnosed participants found the ‘Expense of Cooking’ challenging although cooking is usually considered to cost less than eating out; all but one who answered that expense for cooking is a challenge were those whose incomes
are less than $25,000. Seven diagnosed participants lived in a place where someone else provides meals. Six diagnosed participants found ‘Cooking Dangerous’ while none of the self-diagnosed participants did. ‘Smells from Cooking’ was challenging to six diagnosed participants and one self-diagnosed participant. Four diagnosed participants and one self-diagnosed participant answered that they ‘Do Not Have an Adequate Place to Cook.’ There were several other cooking challenges that were missing in the survey answer options and many participants specified them. Executive functioning issues were most frequently mentioned among them. While executive functioning is related to time constraints because it involves time management skills, other executive functioning related issues such as lack of planning, too, were commonly mentioned as a cooking challenge. Other cooking challenges were lack of energy or strength to cook and touching some raw ingredients.

![Challenges in cooking](image)

*Figure 17. Challenges in cooking*
Below, I will detail four areas of challenges (i.e., executive functions, lack of energy and
dangers while cooking, lack of an adequate place to cook in) based on both survey results and
interview participants’ responses.

Executive functions. When asked about their challenges regarding cooking, several
diagnosed survey participants specified that their challenges are (related to) their executive
functions. Some of them wrote simply the term (e.g., “EXECUTIVE DYSFUNCTION!!!!!!”).
Loren is one of those who find cooking is difficult because of an executive functioning issue. For
them, getting started is particularly difficult: “it's hard for me to get going.” In order to overcome
their issue with executive functions that makes it difficult to start cooking, they uses their logic
to convince themself to cook: “Generally I know I have to eat before I go to sleep and that I can't
cook at work, so if I want to sleep, I have to eat and cook food.” E, a diagnosed survey
participant, detailed her issues with executive functioning regarding food:

‘food’ is definitely one of the most challenging aspects of living for me. I have a lot of
issues with food, and a medical condition that makes eating very difficult sometimes. On
top of that, the executive function necessary to plan a meal, cook a meal, eat a meal, and
clean up after a meal, is quite considerable, and often lacking after a day at work. Your
survey did not touch on this at all, but for me, it's a big challenge to eating regularly and
well! ; I run out of spoons long before food has been consumed.

Another diagnosed participant, too, listed her executive functioning issues regarding cooking:
“planning ahead to have the right ingredients, executive functioning needed to cook, being able
to decide, rapidly changing what appeals to me so that I can't plan more than a day or two in
advance.” Some autistic participants did not use the term, executive functions, but wrote about

29 Running out of spoons means running out of energy in the spoon theory.
some deficits in executive functions (i.e., working memory, time management, organization, planning) as their challenges regarding cooking (e.g., “I sometimes forget that I am cooking, leave the burner on, or have difficulty [sic] with the proper order to cook in”; “a lot of the time cooking calls for impeccable time management and general ease for organization; “Too hungry, lack of planning”). Due to lack of planning, Drew mostly eats food that does not require much planning. *They* called it “easy diet”:

Anything involving gluten is an easy diet. Like pasta. I don't like instant ramen. I don't crave about that. But I had a box of 30. That was the best emergency food. When I ate them, I ate two at a time even though I didn't like.

Into *their* late 20s, *they* lived simply on frozen food, which *they* calls “frozen food diet,” and instant noodles for several years, but it deteriorated *their* health and had to stop eating them.

Lack of planning regarding cooking does not necessarily mean not thinking about establishing a routine of eating certain dishes that are sustainable. Drew said *they* had spent so much time thinking about it but that led *them* to become “so confused and tired” and “get stuck” with only so many variables because *they* tried to come up with their own unlike other people, who “just blindly follow other people.”

On the other hand, lack of planning resulted in waste of food ingredients as well, which made cooking expensive. Drew said, “It is hard to eat vegetable. It is difficult to prepare, it is difficult to...it goes bad quickly. So in the end I eat only starch.”

*Lack of energy.* Some survey participants said they do not have energy for cooking (e.g., “i dont have the energy,” “takes a long time and lots of effort”). In the survey, Daniel did not specify *their* lack of energy as a challenge regarding cooking, but it was one of *their* two biggest challenges. However, when probed about the challenges *they* indicated in the survey (i.e.,
“Cooking is Dangerous,” “Time Constraints,” “Expensive,” “Meals are Provided,” “Lack of Knowledge” and “Lack of an Adequate Place to Cook”), they said they does not cook mostly because they does not have time and energy to cook: “it's a question of spoons: Am I going to devote my limited time and energy to cooking when I can just microwave something and save my efforts for other things?” Drew, who talked about feeling fatigued and being depleted oftentimes in other contexts in this study, said they can make green juice only when they is not depressed. Although they already experienced that green juice boosts their mood and restores their energy, they could not maintain a routine of making juice mostly because it is time consuming and tiring. It requires frequent shopping for fresh organic vegetables, washing and cutting them, extracting juice using a machine, dissembling the machine, cleaning it, and reassembling it. When they is tired or depressed, they does not have energy or motivation to make green juice; they joked, “Those who feel good will feel better and those who feel bad will feel even worse.” Alex said what she cooks is usually based on her energy level or how she is feeling health-wise.

**Dangers while cooking.** Using knives and stoves were considered dangerous by some autistic adults. Sally said Jason, who does not cook, did try to make pasta once but caught a paper towel on fire that was touching the burner. He left the kitchen instead of trying to extinguish it because it scared him. Mastermind said he never cooks mostly because he fears using knives and fire in the kitchen. He has trouble with tightly holding on to objects. Abby, who answered that she drops things and loses her other belongings during grocery shopping, also mentioned that she has trouble with using knives: “I also am very clumsy and tend to splatter things all over. I can't use knives due to coordination issues so I just rip up vegetables.” Drew has no difficulty holding knives or any other objects, but still fears holding a knife bigger than a
steak knife. They feels uncomfortable even when they sees someone else holding a big knife while cooking. They uses only an old steak knife that is not too sharp. Interestingly, Sally reported they have found that using a serrated steak knife works best for Rose, as it does for Drew. But there was a huge difference between Rose and Drew: Rose “loves” virtually all components of cooking whereas Drew finds “the work that is omitted in TV cooking shows” tedious and tiring:

[My daughter] loves to chop veggies!! She uses a serrated steak knife to chop. We have found this to work best for her. She loves to chop potatoes, peppers, tomatoes, any veggies at all! She also loves the process of putting things in the skillet and watching them sizzle. And stirring them. Because of her cutting skills, we make a lot of stir-fry type meals, soups, casseroles and salads. She also likes the process of pan-frying fish or chicken or pork chops. This involves mixing a flour/spice mixture and dipping each piece of fish/meat in the mixture and an egg-wash or milk. That repetitive process and then the sizzle in the skillet is very enjoyable to her. She will also make side dishes to accompany the meat such as a rice dish or potatoes and a salad. She also enjoys making biscuits. The mixing, rolling out, cutting and putting on baking sheet are all good tasks. For weekday breakfasts she makes a yogurt parfait with yogurt, frozen berries, granola and Fiber One, along with a fruit bowl. Weekday dinners depend on what activities we have and what time we get home, but we still like to make it "home-made" or perhaps leftovers from the weekend. Another thing we do is make some kind of lunch salad for her lunch boxes during the week. This is usually a pasta or grain salad with chicken or shrimp and fruit/vegetable. She cooks basically every day of the week, taking
more time on the weekends. As far as hours per week, I would estimate 16-20 hours per week. […]

Despite her cooking skills, those who do not know her cooking skills tended to assume that cooking is dangerous for her. Based on their general understanding of people on the autism spectrum, her visiting caregivers often did not allow her to use a knife or fire at the stove. Sally says, they are later “amazed” by Rose’s skills.

*Lack of an adequate place in which to cook.* Among five survey participants who answered that they do not have an adequate place to cook in, one lives in a college dorm, one lived in a sober house, one lived in a residential facility for people with neurological conditions, and two lived with their partners. Mastermind did not check “Lack of an Adequate Place to Cook In” in the survey but it was an issue. In addition to checking other cooking related challenges (e.g., “Time Constraints,” “Lack of Knowledge,” “Cooking is Dangerous,” “Smells from cooking”), which was same as his response, his mother checked “Lack of an Adequate Place to Cook In” and specified, “The high temperature inside of the kitchen due to oven during cooking.” When I visited their house in summer, I noticed that the kitchen was very small and became hot and stuffy during a cooking time. There was no air conditioner or exhauster in the kitchen. Because the kitchen was very small, the only surface to prepare food was right next to the oven. While his mother or father was cooking in the kitchen, he stayed in his air-conditioned room. She encouraged him to come and help her cooking but he said it is too hot there. High temperature was an issue for another survey participant as well.

*Challenges in growing food.* Growing one’s own food may enable the person less frequent grocery shopping, which can be daunting. Most of the participants, however, currently did not grow food even in part. The various reasons of not growing food were mostly related to
not having own space to grow. Daniel does not live in “a house that is equipped for starting a
food garden.” Loren does not have space or time to grow food at this point. They did not think
about whether they would grow some food: “I'm far off from having my own place.” Alyssa used
to grow food when they lived with their family. They had raspberry, blackberry bushes in the
yard at home, along with black raspberries and some blueberries. They also used to do tomatoes,
cucumbers, peas, pumpkins, and onions. Though now none of her family has much time for
gardening, they keep some plants that are self-seeded, basil, oregano and others that are at least
as easy as grass. They gardened because “it tasted good and because it was often cheaper than
the store.”

Drew does not grow fundamentally because they does not have a steady job. Their
current position is one year contract: “You don't plant when you are pressed. You don't plant
when you think you are moving out.” When they was a teenager, they grew “all the times, all
kinds of items.” The most recent time they tried to grow something was about ten years ago.
They planted watermelon in the backyard of their rented house. But their landlord suddenly
removed everything: “I would have water melon within a month. He never cleaned the backyard
other time. He didn't even see the back yard. But somehow that summer, he had a dream about
watermelon.”

Tony used to grow food, and was “fascinated by the process and delighted with the
resulting bounty.” His first garden was in a girlfriend’s back yard in about 1987. When he bought
his own home, his first project was building a garden and planting privacy hedges. He did the
same with his next two homes. He had stopped growing subsequent to heart surgery in 2002,
then did not have time while he was back in school. “It has since languished,” but he shared a
beautiful memory of growing food in his garden:
I had grown: tomatoes, cucumbers, onions, potatoes, carrots, beets, cabbage, grapes, apples, pears, herbs, pumpkins, zucchini and more. I'd set up soaker hoses on a timer; it was then automatic. A few weeds had to be pulled from the soft, organically enriched soil; I assembled wonderful soil. When I'd get home from work, first thing I'd go into the garden and start munching while I'd feel the vegies growing; spiritual experience.

In contrast, Samantha dislikes touching dirt and finds gardening boring.

The only participant who currently grows food was Sally, along with her daughter, Rose. They have raised beds in their nice backyard and Rose takes a great care of their food garden:

We have a nice, fairly large, sunny backyard! I had tried many years to start a garden out there without much success. The soil is VERY sandy and not conducive to gardening. Then, a few years ago I had a couple of students build us 6 raised beds and filled them with good compost. They worked great! I do need to maintain them and refresh the soil each spring, but they have made a huge difference in our ability to grow. My daughter likes to plant seeds and seedlings, water the plants and pick the produce. Not weeding! I am going to try this year to use a mulching or weed barrier system that weeding wouldn't be so much an issue! It is great when things start ripening and she can see that garden to table connection!

**Summary**

In this chapter, I argued that autistic participants are living in invisible food deserts because their physical and social environments do not accommodate their autism-related characteristics such as sensitivities to various foods and environmental stimuli. Many participants said that they often chose to “go hungry” to avoid challenges in such food environments. A place that does not appear to be a food desert may be experienced as a food
desert by autistic individuals, where their access to edible healthy food is limited. I identified four characteristics of invisible food deserts experienced by autistic adults, and four factors that exacerbate their negative experiences of the invisible food deserts. In the invisible food deserts, the availability of edible foods is limited because autistic adults tend to have restricted diets: almost all of the participants had food aversions due to sensory sensitivity issues and some of the participants avoided certain foods (e.g., meat) for ethical reasons, health reasons or medical reasons. ‘Unsafe’ people who enforce unwanted social interactions or diets further limit their access to desired foods and food places. In invisible food deserts, over-stimulating food places with crowding, noise, too bright lights also are prevalent. Hours of operation of some remaining acceptable places are experienced as restricted: participants tended to go food places at odd time for various reasons (e.g., unawareness of becoming hungry, avoidance of crowds). Negative experiences of the invisible food deserts were often exacerbated by autistic participants’ limited financial resources, difficulty in asking for a change or help, limited mobility due to lack of driving skills, and challenges in cooking and growing food. Low-end places tend to be crowded, noisy and “terribly” bright with fluorescent lights while the choice of foods is limited. The suffering in an over-stimulating environment may continue while not asking for a change or help. Even though eating out involved many challenges, eating at home by cooking was not a feasible option to many participants because they had issues with their executive functions, lacked energy, found cooking dangerous, and/or lacked an adequate place in which to cook. Almost all participants who live in urban areas did not grow their own foods even in part mainly due to lack of space. In the following chapter, I introduce their strategies to survive their invisible food deserts.
CHAPTER VII
STRATEGIES TO SURVIVE IN INVISIBLE FOOD DESERTS

Although eating out and grocery shopping were challenging in invisible food deserts as illustrated in the previous chapter, participants were managing these challenges using coping strategies. Some participants even said they “like” going grocery shopping. The reason that they liked grocery shopping was partly because they have developed some strategies to avoid shopping stressors. For example, Drew said they “HATE[s] going grocery shopping” for various reasons, but “like[s]” grocery shopping because “that is the only activity [they] does other than working.” When they is bored from work, they likes going grocery shopping in the middle of the night just to relax “because there is no other place to go.” In this chapter, I will first report survey responses on strategies to cope with sensory challenges while eating out and grocery shopping. Then, I will categorize the several different coping strategies (i.e., avoiding the source of inputs, blocking inputs, maintaining distracted focus) based on interview responses. Lastly, I will discuss limitations of coping strategies.

Survey Responses on Strategies to Cope with Sensory Challenges

Autistic participants (23 diagnosed participants, six self-diagnosed participants) were asked about some strategies they use to cope with sensory challenges they face while eating out and grocery shopping. Regarding eating out, ‘Taking out food’ was the most frequently used strategy to avoid challenges, particularly among the diagnosed participants (12). Two self-diagnosed participants also used this strategy. ‘Dining at odd times’ was the second most widely used strategy, that of nine diagnosed participants and two self-diagnosed participants. About one third of diagnosed participants (7) answered that they wear ear plugs or noise-canceling earphones to block out noise whereas none of the self-diagnosed participants did. Five diagnosed
participants answered that they wear sunglasses to deal with sensory stimulations. Four diagnosed participants bring their own food when eating out. Sitting in a corner or a booth was the most frequently mentioned strategy by participants among the strategy options that were missing in the survey.

Figure 18. Strategies when eating out

When asked to indicate their strategies to cope with sensory challenges while shopping for groceries, survey participants most commonly answered that they go ‘Shopping in the middle of night or at other odd times’ (11 diagnosed participants; two self-diagnosed participants). ‘Wearing earplugs or noise-cancelling earphones’ was another most frequently used strategy among diagnosed participants while that strategy was not used by any of the six self-diagnosed participant. ‘Wearing sunglasses’ was another frequently used strategy (seven diagnosed participants; one self-diagnosed participant). Half of the self-diagnosed participants answered that they ‘Do not have sensory challenges while grocery shopping,’ which is a contrast to the case of diagnosed participants. Only three out of 23 diagnosed participants answered that they ‘Do not have sensory challenges while grocery shopping.’ When it is considered that one of the
two participants who did not answer this question is a self-diagnosed participant and the other is a diagnosed participant, the contrast is even greater. Shopping one or a few items per visit was not included in the option list, but three diagnosed participants specified that as their strategy to avoid sensory challenges.

Figure 19. Strategies during grocery shopping

Types of Coping Strategies

Evans (1984), an environmental psychologist who has studied environmental stress, listed the following adaptive strategies in an introduction regarding sensory overload: “filtering out low-priority inputs, blocking inputs, increasing routinized, habitual behavior, and attempting to redefine the source of information” (p. 9). Interview participants shared their strategies to cope with sensory challenges they face while eating out and grocery shopping and the reasons behind them, which led me to identify types of their coping strategies. The pattern in the ways participants cope with sensory challenges while eating out and grocery shopping were similar to each other. Below, I categorize their various coping strategies as following: avoiding the source of inputs, blocking inputs and maintaining distracted focus. For each type, I first introduce
strategies for eating out and then strategies for grocery shopping. Most of the strategies entailed some concerns.

**Avoiding the source of inputs.**

**While eating out.** Their strategies to avoid situations with sensory challenges while eating out included taking out food, dining out at off-peak hours, using vending machines and bringing own food.

**Taking out food.** Taking out food minimizes the time one spends in an eatery, which, in turn, enables avoiding prolonged exposure to sensory challenges. While the conception of taking out is “easy,” there were some challenges in actually taking out. Alyssa implied that “being able to last long enough in bad environments to get the food” is not the case with everyone. They said they can do that now because they has started using headphones or ear plugs to bear such environments. In Daniel’s case, they could take out by “overcoming internalized ableism” and giving themself permission to take out. Although taking out is a last resort for some autistic individuals to avoid challenges related to eating out, others avoid taking out for reasons of its high price or low sustainability. Alex said, “My main concern with eating take out is how expensive it is and my boyfriend hates how much waste it creates- but I would rather create waste then [sic] suffer a little bit more.” Samantha wanted take out options without the cashier and counter help in her workplace cafeteria, but take out was “discouraged as not green/bad for the environment.” Another concern on taking out food was ingredients being mixed together inside the take-out container. Daniel explained, “My concerns include ingredients mixing together thus leaving a lowered quality on the parts I can actually eat, and overpaying for a meal when I know going in that half of it is headed for the trash.” Aversion to different foods touching each other was a real issue to Samantha as well even though she did not mention that issue.
regarding take out. While talking about various challenges that add up in cafeteria, she mentioned that “it is not socially acceptable to express displeasure if someone puts two items touching on a plate and hands it to me.” Drew too would not eat when *they* was young if different food items touched on a plate. At least *they* now does not have much issue with foods touching, but avoids take out mainly for price reasons. *Their* workplace cafeteria charges twice if one takes out unlike Alyssa’s school cafeteria for engineering students. Drew eats in the cafeteria to avoid being charged twice even though *they* hates its greasy and smelly atmosphere and encountering unwanted social interaction.

*Dining at off-peak hours.* By dinning at off-peak hours, one can avoid the crowd. Crowding means more noise and unwanted social interaction, and long wait time, which translates to prolonged exposure to these challenges. Sally said going at "off" times is a good idea for Rose because then it is not crowded. Alyssa often eats at odd times. *They* began to eat at odd times because of tight schedules, but soon found it helpful dealing with challenges regarding eating out:

Eating at odd times happened kind of because of schedule issues, and kind of by accident. In college, I have a tendency to wind up with over-determined schedules and not much control over when I'm in classes, […] it was actually so bad that I was registered for two classes that overlapped in meeting times and we had to figure out a way for me to stay registered in both. With that sort of class schedule, food happened when I wasn't in class, often quickly, so I had to eat at weird times. I noticed that places were less crowded, so I could get food faster and it was quieter, when I got food at weird times.
However, the option of eating at odd time was not available to everyone. Drew wanted to eat at odd times at their previous workplace cafeteria, but it operated for such short hours that there was no odd time to eat there.

*Using vending machines.* In order to avoid the “the horror of social chit chat or the chaos of a cafeteria,” Samantha prefers getting food from vending machines as mentioned above. Her current workplace “has limited vending machines to soda and water juice” and provides a 24 hour cafeteria whereas vending machines with breakfast, lunch and dinner were “omnipresent” in NASA and a university lab where she worked. The vending machines in her previous workplaces were “the old style where there were doors that opened and you pulled out a sandwich, fruit, milk, ice cream etc.” and “[a] lot of people who were focused on their jobs [at a science research center] ate out of them.” At the end of the day she would pick up some sort of meat sandwich, fruit, and chips as dinner. No shopping or preparation was required. Compared to Samantha’s previous workplaces, Drew’s previous workplace in the isolated large campus had extremely limited options that were edible for them. Among all the junk foods from the vending machine, popcorn was “the least junky” food. But popcorn was often not available any more at late night and it also left a bad aftertaste.

*Bringing own food.* Daniel came up with the idea of bringing food through “trying to find a way to, as a disabled person, be more accommodating to non-disabled people.” However, they does not bring their own food often because they considers that is “the opposite of how things are supposed to work.” They faced some challenges bringing food. They sometimes does not have much energy left to bring their own food: “spoonie issues make this not always possible.” A limited amount of spoons is a disability metaphor for a limited amount of time and energy a person has in each day in spoon theory by Christine Miserandino (2003). They was also
concerned that most restaurants do not allow outside food. Abby has an issue with bringing food with her even though she wants to do so. She has aversion even to someone else’s lunchbox: “I have an aversion to bringing food with me. Something about lunchboxes and brown bags is triggering for me (not to sound melodramatic, but I feel uncomfortable if someone is carrying a lunchbox).” Luckily, Sally’s daughter, Rose, does not have any issue with bringing her own food, and she actually enjoys preparing her lunches together with her mother, according to Sally. In Rose’s vocational training program, students have to bring a sack lunch and they eat together at a large table in the main communal area. Sally said Rose very much likes having lunch with other students there. There were approximately 12 students in the program and they knew each other well.

**While grocery shopping.** Strategies to avoid exposure to sensory challenges while grocery shopping include shopping in the middle of night or at other odd times, shopping for one or a few items per visit, bringing shopping list, using an automated teller and using online grocery stores.

*Shopping in the middle of night or at other odd times.* Samantha shops in the evening or during major sporting events, such as during Sunday super bowl game, “simply because fewer people, less distractions.” By shopping at night and using other strategies, she could comfortably shop at her favorite grocery store, Walmart superstores, which has one-stop-shopping convenience and consistency in products:

They are quiet [at night]. Everything is stocked and in the same place. I especially like that the one near me has indoor parking and I can get my food, my dog’s food, hardware, cosmetics, and drugs all at once. It is always the same thing, where I remember it, same
brand. I really dislike variety and as long as the quality is consistent and not yucky
normal is normal.

She dislikes “small trendy organic coops,” where she feels they are always crowded, noisy and
smelly. Alex shops around 8pm because it is pretty empty by then. She describes her observation
of the crowds depending on different time blocks in detail:

I have found that all through the week day, maybe 12pm-4pm lots of moms are grocery
shopping with young kids. And from 4pm-7pm (tapering down by maybe 6pm) that
people getting off from work are grocery shopping. So by 8pm its pretty empty and
sometimes picked through, but its worth it for me.

Hannah stated Jason shops at times when the grocery store has the fewest people there, to avoid
being around people. He hates crowds and does not like the eye contact people try to make with
him. Drew has developed a habit of going grocery shopping late and says, “I cannot even
imaging going grocery shopping when there is sunlight.” They particularly avoids going there
Sunday morning: “Everybody decides to go. In the middle of the night it is very empty.” By
shopping at late night, Drew could appreciate positive aspects of their favorite grocery shopping
place in their old neighborhood. In addition to opening for 24 hours, the place did not have
fluorescent lighting, did not stink, carried a broad range of organic produces and organic eggs,
and had friendly but not “intrusive” staff. Some problems at night were that green leafy
vegetables were largely sold out and olive bars and nut bars were closed at late night. The bar
was covered with paper and the tongs would be removed. They did not want to bother an
employee to bring one.

For some participants, shopping at night is not necessarily to avoid crowds if the place is
usually not too crowded anyway. Loren said that night is generally when they has time and the
most energy/momentum. When asked if they is a night owl, which is common among autistic
individuals, they said “Yeah. Even when I wake up early, I'm unable to get to sleep until pretty
late.”

Shopping for one or a few items per visit. By shopping for one or a few items per visit,
one can avoid being exposed to sensory challenges for long. Daniel and a few other diagnosed
participants shop for one or a few items per visit. Daniel explained how that strategy helps them
avoid overstimulation when grocery shopping: “Shopping doesn't take long and I'm usually out
before the sensory aspects start to bother me severely.” However, shopping one or a few items
per visit means having to go grocery shopping more often than one would like. More frequent
visits may mean more frequently waiting in line, encountering cashiers and spending time on the
trip. When asked if they finds those kinds of inconvenience not as bad as staying longer in a
grocery store, they answered that they generally does not have issues with lines or cashiers, other
than the time investment if they is in a hurry. For them, their limited ability to bare
overstimulation is a more serious issue. They compared shopping for a few items per visit to
running a marathon, both of which would exhaust one’s energy, from their point of view:

What matters more to me is getting out before spending all of my spoons\textsuperscript{30}. While one
can "borrow" spoons from the future, it's much more difficult to save them up from the
past. Compare it to preparing for a marathon: An athlete may be able to run a traditional
26-mile marathon, then recover and gear up for another marathon a few months later.

That same athlete may not be able to run 52 miles continuously.
Daniel’s answer possibly reveals how Rose feels when she sometimes “tries to move quickly to
get out as soon as possible” during grocery shopping. Without intending to, Sally and Rose

\textsuperscript{30} A metaphor for a limited amount of energy or time of a person with a disability or chronic illness
sometimes buy only a few items: “She also tries to move quickly to get out as soon as possible, which means we sometimes don't get everything on our list!”

_Bringing a shopping list._ For many participants, knowing exactly what one is going to purchase in a grocery store was critical. Having a shopping list helped figuring out what to buy, and, in turn, helped minimizing shopping time. My interview with Loren was done right after they came back from a grocery shopping. When asked about their grocery shopping experience that day, they said, “Pretty good. I knew exactly what I was going to get, so it helped.” When asked if they dread less when having a shopping list, Drew said, “Of course! If I know what to buy, I'll not dread much.” For them, having a shopping list is so critical that when someone took their shopping cart that had their shopping list, they became extremely upset and had a meltdown in a grocery store. They was not used to shopping for groceries at that time though experienced enough to come up with a shopping list.

_Using an automated teller._ One way to avoid unwanted social interaction with cashiers and waiting in line in a grocery store was using an automated teller. However, Samantha had a bad experience with using an automated teller in a recent, annoying experience. Considering that she says she likes using vending machines because she can get food without the horror of social chit-chat in a cafeteria, her answer might sound counter-intuitive. But her answer is not surprising because she is sensitive to noise and light and does not like things that are unnecessarily artificial: “I had to use an automated teller and it beeped and flashed red every time it scanned something and had a mechanical voice. After about half a cart load I left.”

_Using online grocery stores._ A way to completely avoid sensory challenges while grocery shopping is using online grocery stores. Alyssa frequently uses an online grocery store, PEAPOD, and is satisfied with that option. The online grocery store is their favorite grocery
store for its delivery service: “Mostly because it delivers and then I don't need to actually go to a
grocery store. Buaha!” They had no concern about using the online grocery store: “I'm really,
really unconcerned about using this strategy because it does everything I need it to do. I get food,
and I don't need to go to the grocery store.”

In contrast, Alex feels guilty about using online grocery stores because she thinks she
needs to support her current local business:

In a guilt free world I would do all my shopping online. […] I feel that as someone who is
living in a neighborhood which I did not grow up in, I feel that I need to support local
businesses since I am living here (as opposed to buy groceries online from a huge
corporation like amazon fresh).

She was informed that she won one of the 20 eGift cards for participating in this research, but
could not easily choose her favorite eGift card. She asked me to give her more time to think
about what to choose. It took more a month for her to choose one while most other winners
chose and replied to me within a few days.

Abby, who has limited financial resources, had a concern about online grocery being
more expensive: “The idea of online shopping is great, but I can't do the expense.”

**Blocking inputs.**

**While eating out.** Many participants attempted to block out sensory stimulus by wearing
earphones, wearing sunglasses, sitting in a corner or booth and going on mental autopilot.

**Wearing earphones.** As a strategy to eat out more comfortably, Alyssa wears noise-
canceling earphones when they eats out though not during chewing. They usually wears noise-
canceling earphones when they is in public, and they happened to be listening to music when
they entered a restaurant and found wearing them helpful dealing with the restaurant
environment. The reason they wear them while getting food but does not wear while eating was because then “the chewing sounds get amplified.” They is also generally “weird” about wearing things while they eats: “I can wear a long sleeved shirt, but not a jacket, and I can't have anything on my head, when I'm eating. Not sure why.” Loren too wears a headset when eating out to block out sound. When asked if there is any concern about using that strategy while eating, they talked about other people’s reactions: “People don't tend to mind -- I've only had one person try to push them off my head -- because I think they assume because I look disabled that I've got stuff going on so they don't bother me about it.”

Wearing sunglasses. Daniel is one of the participants who answered that they wear sunglasses when eating out to deal with sensory stimulation. Daniel’s concern regarding wearing sunglasses was being understood at American Sign Language events. Facial expressions such as squinted eyes play a critical part in the meaning of a sign.

Sitting in a corner or a booth. One diagnosed participant sits in a booth as well as wearing tinted glasses: “I ask to sit in areas that I know won't bother me as much (booths because I'm not surrounded by other diners as I would be at a table, seats where the lighting is more suitable, etc.).” Another diagnosed participant answered that she sits only in certain types of seats (e.g. with my back against the wall) in addition to eating only with “people who can help not make sensory challenges worse.” Samantha likes to sit in corner booths to avoid internal air flow, noise and stimulation, and having corner booths is one of the criteria of her favorite restaurants:
I realized early on that internal air flow, noise and stimulation from all over annoys me.
The best idea ever came from a western where one character always kept their back to the wall. I came to love corner booths and places with corner booths.

While being able to handle eating at most places, Alex too finds sitting in a corner helps her eat comfortably. She generally does not like places that are too “sterile and corporate” but she goes such places if they have “booths that are deep and usually empty allowing [her] to eat with some ease and comfort.” However, she often did not have control over where she sits when she eats out with others:

Usually my biggest complaint, in my head never really said out loud, is where I end up sitting. Sometimes you can’t control where you sit and I’d rather be less of a bother and deal with it internally than have it be exposed and possibly troublesome to others.

When she ends up sitting in overwhelming seating locations, she becomes self-conscious, and forces herself to believe that she is feeling comfortable:

[…] if I am sitting in the middle of the room or a high traffic area I feel very aware of my body, my posture, my joints, how my legs hang off my chair. I find ease by being able to cross my legs or by lifting one leg up on my chair. It’s like I feel uncomfortable, so I convince myself that I feel comfortable by over compensating by sitting in “comfortable positions.”

Loren has many reasons for liking their favorite restaurant, Lo Porto. In addition to having “amazing pasta sauce and bread, that place has people who really like [them],” and give them a corner seat so they does not feel surrounded by people even when the place is crowded. They won’t schedule anything else on Friday night unless they has to leave town. In their other

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31 So one can see who is entering and therefore that one is not shot from behind.
two favorite places, they can sit in a corner or in a table against a wall. By sitting in those, they can easily “avoid feeling trapped” because that way they can see anything that is going to make sound or touch them.

Sally too answered that her daughter, Rose, copes with sensory challenges by sitting in a corner, particularly near the door to avoid walking past the crowd. In her favorite restaurants, she has “her” table and almost always sits there:

Haha, it is funny when she goes to certain places that have "her" table! If someone else is sitting there she will still go to that table and just look at them, as if to say why are you sitting at my table. She is usually pretty open to going to another table though, since these places are ones she is comfortable at. As far as being close to the door in an unfamiliar place, we don't have to walk past a bunch of other people and it is usually less congested near the door and we're surrounded by a lot of other [empty] tables.

**While grocery shopping.** Strategies to block out sensory challenges included wearing sunglasses and wearing earplugs or noise canceling earphones.

**Wearing sunglasses.** Daniel wears lightly tinted glasses in case the lighting starts to bother them while they is in a grocery store. Samantha wears sunglasses while grocery shopping and has no concerns about that strategy. She would stim in a subtle way if light is not properly filtered through sunglasses.

While some participants did not have concerns regarding wearing sunglasses while grocery shopping, others had. Abby, who “just hated fluorescent light,” likes to wear sunglasses while shopping for groceries, but has a concern about her being visibly identified as a disabled person:
I go to the store so infrequently that I haven't really perfected a good strategy. I like to wear sunglasses, but I don't do this if it is a cloudy day or if it is nigh time. I'm ashamed to say it, but I worry people would visibly identify me as disabled.

Drew used to wear photochromic glasses, which darken on exposure to ultraviolet (UV) light, because of their sensitivity to light. But they has stopped wearing them since a “lousy” optician, who put a lens for astigmatism in a wrong angle by 180 degree and caused them much real headache for several months, now replaced it with a non-photochromic lens in their glasses. They said they looked like “the Target dog” under the sun during a vacation because the non-photochromic lens would not turn dark. That was “the last straw.” They could not bear the inconvenience related to that special lens any more. They had already not liked wearing photochromic glasses because they found it inconvenient to wait until the lenses become transparent. On top of that, other people had noticed how recently they entered a building based on the color intensity of the lenses.

Wearing earplugs or noise canceling earphones. Alyssa wears headphones to block the noise when grocery shopping. They has a minor concern with headphones, which is being a target of some predators:

I know some predators take earphones to be a sign that someone is not paying attention and is therefore easy prey. It's minor because I can actually still hear people moving near me so I'm not actually easier to sneak up on or anything when I wear the headphones, they just might think I am.

Samantha wears earphones to reduce the noise and keep people at a “safe” distance: “Ear phones make it less likely or someone to approach me. The ear phones or buds just seemed like a way to

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32 A dog with Target’s bullseye logo painted around her left eye
solve the noise problem and keep people at a safe distance—less overwhelming.” Again, she had no concerns about wearing them when grocery shopping.

**Maintaining distracted focus.**

**While eating out.** Many interview participants answered that they just leave the eating place with sensory challenges if they are alone. During social situations, however, the option of leaving the place was often unavailable. In social situations, strategies mentioned above also were not feasible. In such situations, they had to cope with sensory challenges mainly by trying to maintain distracted focus. Sally’s daughter, Rose, recently could not immediately leave an overwhelming bar and grill type place when Sally’s boss was having a birthday party/dinner that they attended at. Rose coped with the situation mainly by maintaining distracted focus. But her coping strategies were described as “negative behavior”:

> It normally wouldn't have been that bad of an experience, but just because of the number of people, the noise and the chaos she was very uncomfortable and wanted to leave right away. When we couldn't leave immediately, she started up with some negative behavior (making a mess with her soda, tearing up napkins, overeating appetizers that were for every one and constantly grabbing my hand or arm for my attention, and then going in the bathroom and not coming out).

Samantha talked about a similar situation, when asked if she tries to change a situation that is annoying to her while eating out. Like Rose, she tries to pay attention to other things and one of the items she uses was napkins:

> First of all if I have to be in such a place assume I have no choice and am forced (Business function, Yacht club banquet, etc.). Since I am there and cannot leave I have to give up being angry and trying to control because the irritations from trying to change the
situation is only going to make me mad. I often take half a Xanax and try to meditate, bite part of my cheek, stim discreetly etc. anything to maintain a distracted focus. Sometimes I start funny games with my table mates like bingo cards of buzz words the bosses use a lot on napkins or flipping change into a glass, etc. Normally if under free will I will feel the vibes of such a place and leave so the problem does not arise.

*Going on mental autopilot*\(^{33}\). On a mental autopilot state, one acts without self-awareness. Going on autopilot is a way to mentally block out inputs. However, it had negative aftereffects. Alyssa said *they* goes on “autopilot” when *they* cannot leave the place with people who do not understand *their* sensory challenges and need for leaving the place. :

If I was on my own, I left and was hungry instead. With family members who don’t get it, I tend to go on autopilot, which isn't actually good for me. However, it gets me through the situation, and all the bad stuff waits to hit until I get off autopilot. This tends to mean melting down or shutting down as soon as I'm alone.

Going on autopilot happened often while grocery shopping.

*While grocery shopping.* Focusing on a shopping companion was the main way to maintain distracted focus while grocery shopping. Hannah said Jason shops at Publix to buy his pasta about twice a month though he never likes grocery shopping. He always goes grocery shopping with his grandfather because he is “not independent enough” according to her. Other autistic participants shared some other reasons why they go grocery shopping with someone or some benefits of relying on someone during grocery shopping. Daniel mentioned that relying on a partner during grocery shopping helps *them* deal with sensory overstimulation. However,

\(^{33}\) Autopilot is originally a system that controls the course of a vehicle without human pilot’s constant control being required.
shopping together with a partner is not one of their coping strategies. Rather, “staying through an uncomfortable grocery run” happens sometimes when they is with a partner there; as mentioned above, they usually buys one or a few grocery items per visit to minimize their shopping time. When they feels overwhelmed in a store while together with a partner, they “either turn [their] brain off and rely on [the partner], or leave and wait in the car.” When asked to tell more about how they turn off their brain in such a situation, they explained two aspects of turning off their brain in the context of grocery shopping:

Most importantly I am giving myself permission not to expend any mental energy for typical shopping tasks like searching, reading, accessing memory, and making decisions. In this context, “turning my brain off” also means consciously (perhaps “brain off” is somewhat a misnomer) narrowing my attention to just my partner and perhaps the shopping cart, rather than welcomed the deluge of sensory information available.

Though Alex has less severe sensory sensitivity issues than Daniel, and she and her boyfriend use grocery shopping as a “small way to spend time together” while both being very busy. She echoed the benefit of paying attention just to the partner during grocery shopping:

[…] I have also found that if I direct my energy and attention toward him then I am less likely to direct it toward all the little things that make grocery shopping an uncomfortable and jarring experience. I have often found that if I direct my attention on something specific I am able to overcome an issue.

These two autistic adults’ answers reinforce that Sally’s guess was correct on the reason why her daughter, Rose, always wants to be holding onto a cart when she feels uncomfortable, while the autistic adults’ answers being more explanatory. Sally stated,
Her biggest thing in grocery shopping when she feels uncomfortable is she always wants to be holding onto the cart. I think it comforts her. Even when she is reaching for an item on the shelf, she still keeps one hand on the cart.[…]

In “too big” chain-type stores, Rose looks “kind of lost” because of “too much activity, people, "stuff" and unfamiliarity” she does not choose anything and “basically just follows [her mother] around.” Sally said it seems like Rose “loses all her independence skills” in such grocery stores. In their Organic Food Coop and a small locally owned neighborhood store, which are her favorite stores, she is not overstimulated by the settings and is more independent:

She can easily negotiate the store on her own (although I or staff are always in the store nearby, she feels comfortable going off on her own to look for items), she knows where everything is, there are fewer shoppers and therefore less activity, the clerks and stockers are all very friendly and take the time to chat with her and know her by name (and the same ones are typically working). I'm also thinking the atmosphere is just more gentle at these places - lights are not as bright, not so much "stuff" cluttering the aisles and they even have smaller grocery carts. She also likes the prepared foods deli where she can point to a dish for perhaps her lunchbox the next day. (Haha, deli staff know her favorites!)

**Limitations of Coping Strategies**

Although coping strategies helped the participants survive in invisible food deserts, there were concerns regarding them. In this section, I will categorize the areas of concerns on using coping strategies and discuss costs of coping strategies.

**Areas of concerns on using coping strategies.** There were several areas of concerns regarding some participants being reluctant to use some strategies or giving up using them. First,
there were social psychological reasons. Abby was reluctant to wear sunglasses in grocery stores because she was concerned that other people might recognize that she has a disability. Alyssa and Mastermind’s mother mentioned that there is a possibility that people who are wearing earphones or noise cancelling headset become a target of predators. Alex wants to use online grocery stores to avoid sensory overload in grocery stores but feels guilty about using them because she thinks she needs to support local business. She also wants to take out food to avoid noise and crowding in restaurants but she is discouraged from doing so by her boyfriend who thinks take out creates too much waste. Samantha, too, prefers taking out food but her workplace cafeteria discourages taking out food for an “ecological” reason.

Second, some coping strategies were not affordable. Abby, who has a low income, said she cannot afford the extra expenses of online grocery shopping. Daniel’s favorite restaurant is Olive Garden because of its food that pleases their sensitive taste and soft ambient atmosphere, but could not eat there as often as he would like due to his limited financial resources. While these two participants are college students, whose incomes are generally low, many autistic survey participants who are not students, too, had low incomes and reported price as a challenge for them to comfortably eat when they eat out. Both restaurants and grocery stores tend to have better or worse ambient environments according to their affordability.

Third, most participants did not ask for changes or help when they were in annoyingly overstimulating places, partly because of what can be called “learned helplessness.” Persons whose coping efforts have failed have reduced perceptions of control over environmental stressors and, in turn, have learned helplessness (Cohen, Evans, Stokols, & Krantz, 2013). Autistic people are prone to learned helplessness (Koegel & Egel, 1979). Many of the participants said that attempting to ask for changes only makes them more frustrated because
they know the situation would not be changed. Additionally, making complaints drains and depletes *them* because it involves social interactions, which they dread especially if they are going to be negative ones. With learned helplessness, *they* did not want to ask for a change, which would only exhaust *them*.

In addition to these areas of concerns shared by the participants, there were other hidden costs of using certain coping strategies.

**Costs of coping strategies.** According to adaptive cost hypothesis, although humans can often adapt to stressful conditions, there are cumulative costs of adaptation to stressors (Cohen, 1980). Such adaptive costs are revealed in aftereffects from stressors (Cohen, 1980). Costs of adaptation to sensory overload were evidenced in the autistic adults. When asked about their concerns with regards to using some of their coping strategies, autistic participants shared examples of aftereffects. For example, while being on autopilot (a coping strategy in an overstimulating environment), Alyssa usually has difficulty in making decisions. After being on autopilot for a while, *they* often had meltdowns as soon as *they* could be alone. For Daniel, there were no perfect coping strategies other than avoiding situations that would involve overstimulation. Even when *they* used coping strategies, such as turning off *their* brain, just focusing on the shopping cart and then following *their* partner, *they* felt all *their* “spoons” were being used up. By avoiding places that are overstimulating, the autistic adults lost opportunities to be with other people. Especially given that “social situations revolve around food,” as Daniel noted, avoiding various food places that are usually noisy and crowding often resulted in social isolation. Social inclusion is critical for one’s health. When asked about health, *they* said *their* health is increased by *their* communities: “My health is increased by my communities, including
those I've found and those I've built, by my close circle of non-autistic friends, by my personal therapist, and by my roommate/fiancé.”

Summary

Participants used various coping strategies to survive in invisible food deserts. In this chapter, I categorized their different coping strategies and discussed limitations of coping strategies. Their strategies to avoid the sources of sensory challenges while eating out included taking out food, dining out at off-peak hours, using vending machines and bringing their own food. Their strategies to avoid exposure to sensory challenges while grocery shopping include shopping in the middle of night or at other odd times, shopping for one or a few items per visit, bringing a shopping list, using an automated teller and using online grocery stores. While eating out, many participants attempted to block out sensory stimulus by wearing earphones, wearing sunglasses, sitting in a corner or booth and going on mental autopilot. Strategies to block out sensory challenges in a grocery store included wearing sunglasses and wearing earplugs or noise canceling earphones. When strategies to avoid the source of inputs or block inputs were not feasible, several participants made efforts to maintain distracted focus. Although using coping strategies is essential to survive in invisible food deserts, there were concerns and hidden costs regarding them. The reasons of concerns of using certain coping strategies included social psychological reasons, limited financial resources, and difficulty in asking for changes or help when they were in annoyingly overstimulating places. These areas of concerns were largely overlapped with the exacerbating factors discussed in the previous chapter. Some of the hidden costs of coping strategies also seemed to include widening of the area of invisible food deserts.
CHAPTER VIII

DISCUSSION

I explored foodways of adults on the autism spectrum in order to understand how autistic adults negotiate and navigate their food environments. In this chapter, I will summarize the main findings with regard to the research questions and make general conclusions. I will also discuss the strengths and the limitations of this study. I will close this chapter with implications of this study and suggestions for future research.

Discussion of the Main Findings

The findings on autistic participants’ foodways revealed that they live in atypical food deserts, which I call invisible food deserts. A place that does not appear to be a food desert may be experienced as a food desert by autistic individuals, where their access to edible healthy food is limited. I identified the following as the characteristics of invisible food deserts experienced by autistic adults in this study were the following: (a) limited availability of edible foods due to restricted diets; (b) ‘unsafe’ people who enforce unwanted social interactions or diets; (c) over-stimulating food places; and (d) hours of operation experienced as restricted. Negative experiences of invisible food deserts were often exacerbated by the following: (a) limited financial resources; (b) difficulty in asking for a change or help; (c) limited mobility due to lack of driving skills; and (d) challenges in cooking and growing food.

In order to survive in invisible food deserts, the participants used various strategies to cope with environmental stressors. They used strategies that I identified as avoiding the source of inputs, blocking inputs and maintaining distracted focus; another common type of strategy, “filtering out low-priority inputs,” (Evans, 1984, p. 9) was not mentioned as their strategy possibly because autistic people cannot easily filter background sensory information
(Bogdashina, 2003), which might have increased the need to use the types of coping strategies that I identified. The in-depth interview responses from the autistic participants on their foodways and coping strategies also provided insiders’ insights on the reasons behind autistic individuals’ routinized, habitual behavior, which is another type of strategy identified by other scholars but not in this study as a separate type of strategy. Participants’ routinized, habitual behavior seemed to be rather the final pathway of their efforts to avoid sources of stressful environmental inputs (e.g., avoiding the crowding and noise of grocery stores by going to a certain grocery store at a certain time with a certain person and purchasing a certain number of items) or to maintain distracted focus (e.g., playing with napkins at overstimulating eating-out places). Regardless of whether routinized, habitual behavior is a type of coping strategy or the final pathway of other type of coping strategy, such behavior seem to be a way to survive in unsupportive environments rather than a deficit to be pathologized.

The finding that autistic adults often live in invisible food deserts, where the availability and affordability of healthy food, is a matter of great concern given that autistic adults’ health-related quality of life is low. According to a recent study (Croen et al., 2015) that compared the health status of adults with ASD ($N = 1,507$) to controls ($N = 15,070$), adults with ASD had “significantly increased rates of all major psychiatric disorders including depression, anxiety, bipolar disorder, obsessive-compulsive disorder, schizophrenia, and suicide attempts” and “nearly all medical conditions were significantly more common in adults with autism, including immune conditions, gastrointestinal and sleep disorders, seizure, obesity, dyslipidemia, hypertension, and diabetes” (p. 814).

Autistic participants who are against the ‘cure of autism’ strongly opposed to a claim that certain diets ‘help with autism,’ but they were aware of health issues common among autistic
people and said certain diets may help with such conditions. They differentiated cure of health problems common among autistic individuals from ‘cure of autism,’ which is in line with opinions of other autistic individuals including KenG (2011), who wrote “Curing medical conditions which are common among Autistics is totally different from "curing" Autism. Nobody objects to curing such medical conditions, but you need to be explicit about the huge differences between such conditions and autism itself” in a response to Dana Marnane of Autism Speaks. Some participants further differentiated ‘autistic ways of showing distress’ from autism itself and suggested that distress is a result of the over-stimulating environment, hunger, or health issues including pain, gastrointestinal issues, allergic reactions or sensitivities to certain foods. The participants’ beliefs on the relationship between diet, autism and health shed light on a way we can overcome the dichotomy of pro-cure and anti-cure of autism and move towards thinking about environmental issues that influence diet, autism and health.

While participants had different opinions about whether autism needs to be treated, most of them answered that ‘Autism is a way of being.’ Jim Sinclair’s (1993) main message that autism is a way of being, which was addressed in his essay Don’t Mourn For Us, seemed to be widely accepted by most of the participants:

    Autism isn't something a person has, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with.
This is important, so take a moment to consider it: Autism is a way of being. It is not possible to separate the person from the autism. (Autism is Not an Appendage section, para. 1-2)

Several participants who answered that ‘Autism is a disability’ emphasized that autism is a disability in our society due to lack of support rather than because autistic people are intrinsically disabled. The findings on the participants’ conceptions of autism and beliefs on the relationship between diet, autism and health suggest that the current food environments need to be changed in order to accommodate autism-related characteristics so that they can have better access to food and food places that may reduce their distress and benefit their health.

Reducing autistic adults’ distress by creating a stress-reducing food environment may be a critical step in cutting a vicious cycle that worsens their health-related quality of life, because stress impairs executive functions. Executive functioning issues were frequently mentioned by autistic participants as a reason why they have difficulty regularly eating, going grocery shopping, and cooking a meal. Executive functions have been defined by scholars as a set of top-down cognitive processes associated with frontal brain networks for attentional control, inhibitory control, working memory, and cognitive flexibility (Diamond, 2013). Individuals with impaired executive functions have difficulty implementing “real world” activities of daily living (including shopping and cooking a meal) because of deficits in planning, self-correction, goal attainment and decision making abilities (Doherty, Barker, Denniss, Jalil, & Beer, 2015).

Although the conventional belief is that brain is genetically or innately determined, which is consistent with that of most of the autistic participants who answered that ‘Autism is a brain condition’ and ‘Autism is hardwired,’ executive functions have been found to be influenced by external factors. In a recent annual review of executive functions (EFs), Diamond (2013)
emphasized that stress, along with lack of sleep, sadness, loneliness, and being physically unfit, impairs executive functions. She noted that their deleterious effects have been evidenced “at the physiological and neuroanatomical level in prefrontal cortex and at the behavioral level in worse EFs” (p. 153). When executive functions do not work well, one would go on “automatic pilot” and not make effortful decisions (Diamond, 2013). Stressful food environments indeed seemed to at least temporarily further impair executive functions of autistic adults in this study. Daniel would “turn off” their brain, “giving [themself] permission not to expend any mental energy for typical shopping tasks like searching, reading, accessing memory, and making decisions” and relies on their partner when they happens to have to stay in an overstimulating supermarket for long. Alyssa goes on “autopilot” when they is in an overwhelming supermarket. Sally said Rose seems to “lose all her independency skills” in a large, unfamiliar, overstimulating supermarkets and just follows her mother around whereas she is capable of finding all their regular items when they shop in locally owned small stores and their organic cooperative. Executive functioning experiences of autistic adults in this study during grocery shopping in overstimulating stores were similar to those written by the autistic authors. Daniel Tammet (2007, p. 220), an autistic savant, writes in his memoir Born on a blue day that he would regularly “switch off and become anxious and uncommunicative” in supermarkets. Because he is challenged by “the size of the store, the large numbers of people and amount of stimuli around [him],” he goes to “smaller, local shops, which are much more comfortable for [him] to use.”

One of the principles to create a food environment that reduces stress may be supporting autistic individuals’ desire to have control over social interaction and privacy. Paying attention to autistic individuals’ desire to have control over choosing the company of others or having solitude, which is related to self-determination, Steele and Ahrentzen (2016) suggested offering
various opportunities to control social interaction and privacy for an autism-friendly environment. Many autistic participants’ favorite eating-out places had booths where they can sit so that they can more easily control social interaction and privacy, and sitting in a booth or corner was a common strategy to avoid sensory overload. Emphases on creating environments that would support feeling free to enter and exit social interaction and control the level of environmental sensory stimulation have been made since early works in the field of environmental psychology where architects, social scientists, and researchers worked together to create a built environment that would work better for people, including psychiatric patients living in a mental hospital, whose desire for social interaction has been neglected (Architecture-Research-Construction, Inc., 1976; Bakos, Bozic, Chapin, & Neuman, 1980). I agree to the belief of Steel and Ahrentzen that privacy as “selective control of access to the self or to one’s group” (Altman, 1975, p. 18) is a useful approach to create an environment where autistic individuals can choose being social or being private. According to Altman’s privacy regulation theory, a person seeks an optimal level of privacy, where the person’s desired level of privacy and actual level of privacy meet. When the person’s desired level of privacy is higher than actual level of privacy, the person feels crowding. When the person’s desired level of privacy is lower than actual level of privacy, the person feels lonely. Altman’s definition of privacy is particularly relevant to autistic individuals because feeling lonely is not what autistic individuals want though they generally desire an environment that reduces overstimulation. Although a common belief about autistic people is that they prefer being alone, autistic authors and some participants revealed that such generalized belief is likely to be wrong. In his memoir, John Elder Robison (2008) writes,
Many descriptions of autism and Asperger’s describe people like me as “not wanting contact with others” or “preferring to play alone.” I can’t speak for other kids, but I’d like to be very clear about my own feelings: I did not ever want to be alone. And all those child psychologists who said “John prefers to play by himself” were dead wrong. I played by myself because I was a failure at playing with others. I was alone as a result of my own limitations, and being alone was one of the bitterest disappointments of my young life. (p. 211)

Some participants shared their desire to be around people while keeping a certain distance from them as well as their desire to be in an environment without unwanted overstimulation which can be draining. Tony, who is socially isolated and desperately wants to meet “the others” who are like him, said “I'll go to grocery stores and malls just to be around people; I'm unlikely to be called upon to socialize, and when I am, especially by a pretty girl who acts interested, I do little more than slink away (appears haughty or aloof)…” Drew often said they is “noni” juice; noni is a tropical fruit name, but is also their made-up Konglish pronunciation of “lonely.” Though they often jokes that I need to go and increase my knowledge and come back to talk to them, they likes my companionship when they wants, “like a cat.” As mentioned before, Mastermind considered himself to be on the autism spectrum because he feels he is an “outcast of society,” but very much enjoyed the times we had together while we revised the survey questions and interview questions or just hung out together. My understanding was that the kind of interaction he does not like are interactions with people who do not understand his differences, interactions over which he does not have control and interactions that happen where he experiences sensory overstimulation. When I asked him if my understanding was correct, he said I am one of the few persons in the world who understands him.
The findings suggest that overall, an autism-friendly food environment is one where a wide range of individual neurological differences is respected and their freedom of choice regarding safe food and control over levels of sensory stimulation is supported. In other words, an autism-friendly environment is an environment that would have increased options over present environments. An autism-friendly environment in which environmental accommodations are already embedded might be better for everyone regardless of one’s level of autistic traits as universal design is “usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (Center for Universal Design, 1997).

**Strengths of the Study**

This study has several strengths. A strength of this exploratory study is that some of what I have indicated does not conform to a medicalized view of autism, because I could directly hear the “voices” of autistic adults by overcoming the limited view of autism and deliberately avoiding pejorative language regarding autism. As mentioned in the research method section, one of the conditions where exploratory research is preferred is “when a group, process, activity, or situation […] has been largely examined using prediction and control rather than flexibility and open-mindedness” (Stebbins, 2001). While social and communication difficulties is defined as a core characteristic of autism by DSM-5 (APA, 2013), the primary participants were 23 adults highly educated with a formal autism diagnosis and six and self-diagnosed adults. I could hear their voices by using an online survey, online interviews and in-person interviews, through which they were able to “speak.” The autistic participants about their experiences brought great insights because their firsthand everyday experience with disabling environments made them experts about their lived experience and coping strategies, as individuals with disabilities provided invaluable insights in universal design process (Ostroff, 1997). Although some scholars
(Gilber, 2004; Goodley, 1996) pointed out the communication impairments of the autistics and warned to use personal narratives of the autistics with great caution, narratives of many autistic individuals that deal with their challenges regarding sensory sensitivity and their coping strategies became a great form of input. In fact, many characteristics of communication “problems” of autistic individuals, such as talking extensively, odd prosody, and unawareness of when and how to interrupt, were not problems in written texts. Autistic individuals know best in which environment they feel more comfortable and welcomed. This study is to move toward an autism-friendly food environment.

Based on the participants’ detailed accounts that revealed their lived experiences in their food environments, I was able to identify the characteristics of invisible food deserts and the factors that exacerbate the negative experiences of invisible food deserts. For example, I illustrated interactions between autistic participants’ limited financial resources and qualities of food environments such as harsh fluorescent lighting which in turns contributes to overstimulation that they try to avoid. Identification of these issues and the ways they interact may be a first step in dealing with the complex issues of autism, health and the food environment. Identification of “specific mechanisms by which geographic, architectural-technological, and sociocultural factors influence health and illness” (Stokols, 1992, p. 12) and development of “integrative models that address the joint influence of personal and environmental factors in health promotion and disease etiology” were suggested as important approaches in understanding the environmental dimensions of health promotion (p. 14).

**Limitations**

Although the findings of this study provide valuable insights on foodways of autistic adults and how they negotiate and navigate their food environments, the findings need to be
interpreted with caution because this study is exploratory research with several limitations. The first area that requires caution is the number and source of participants. This study was a mainly qualitative study with a small number of participants, accessed online. Also, participants with a diagnosis of Asperger’s syndrome, those who are white, those who are highly educated, those under age 35 and autistic bloggers were oversampled partly due to the online research method, which was employed to accommodate the autistic participants’ communication preferences. The oversampling of these populations has been raised as a limitation of online research on autistic adults (Kapp et al., 2012).

Although it was a significance of this study to hear autistic adults’ marginalized voices in the autism discourse that has been dominated by the medical model of autism, the oversampling of autistic bloggers could have biased results regarding conceptions of autism. It needs to be noted that the responses from some diagnosed participants who were frustrated and expressed desire for cure of autism had a different history of autism diagnoses from the majority of the participants: Most of those with the minority opinion were diagnosed with an autism spectrum condition when they were children; some of those who received an autism spectrum diagnosis when they were adults but shared the minority option include a person who received “special education” as a child and a person with a non-verbal learning disability and “life threatening” muscular coordination issues.

Another area that needs caution regarding the characteristics of the participants is that this study included some self-diagnosed participants while the research question was about adults on the autism spectrum. In order to prevent any confusion, I repeatedly differentiated formally diagnosed participants from informally diagnosed ones using the words, “diagnosed participants” and “self-diagnosed participants,” as necessary when I was reporting the results. But, I did not
design this exploratory study to focus on comparing differences between formally diagnosed participants and informally diagnosed ones and generalizing the differences. I included informally diagnosed participants as well as formally diagnosed participants because many autistic adults do not have official diagnoses (Brugha et al., 2011; Lai & Baron-Cohen, 2015) and the ultimate purpose of this research was to contribute to developing a concept of an environment that is friendly to individuals on the autism spectrum, which also maybe friendly to individuals at the “borders” between autism spectrum conditions and broader autism phenotype (Lai & Baron-Cohen, 2015) by exploring how adults who consider themselves on the autism spectrum negotiate and navigate their food environments. Given that the definition and the diagnostic criteria of autism have been constantly changing, even some of those who have been diagnosed with autism spectrum disorders based on DSM-IV might lose their current autism diagnosis or gain another diagnosis—either another autism diagnosis, social communication disorder or something else—based on DSM 5 or future DSM editions; a study that reanalyzed epidemiological data suggests that some children previously diagnosed with an autism based on DSM-IV would be diagnosed with social (pragmatic) communication disorder (Kim et al., 2014).

A study with more participants on diverse positions on the autism spectrum and with diverse demographic backgrounds would likely better answer the questions of this study. Not having any non-speaking autistic participant who completed the survey is another limitation of this research. The only non-verbal autistic person in this study was Rose, whose mother participated and provided very detailed information about her. Another limitation of this current study regarding participants is that its text-based online survey method might have excluded participation of autistic individuals who are picture-based or those who have limited access to the Internet or do not feel comfortable with sharing personal information online. Lack of comparison
group is another limitation of this research. Without neurotypical participants, it is not clear which of the findings are specific to autism and which are general issues.

The second area of limitation regards the self-report nature of this study. Information about official autism diagnoses of the participants were self-reported. Except for Mastermind, I did not see any of the diagnosed participants’ official diagnoses documents. Any adults who are able to communicate in written or spoken English and consider themselves to be on the autism spectrum were eligible to participate in this study regardless of their official diagnoses. I verified the participants’ likelihood of being on the autism spectrum by asking them to complete the RAADS-14. However, reliability of the RAADS-14 scores of the participants remains uncertain. The RAADS-14 is, again, self-report. Many participants also considered the questions of the RAADS-14 problematic.

Implications

Although the findings of this exploratory study are not definitive, this study has several implications. First, the findings have implications for scholarship about food deserts. Research on food deserts has focused on the relationship between objective health outcomes and access to supermarkets and restaurants. There have been mixed results on the relationship between the two measures. This study on foodways of autistic adults showed that mere existence of supermarkets or restaurants does not lead to actual access to foods that may benefit health. Social, physical and temporal dimensions of these food places explained the reasons why they have difficulty in accessing the foods, which often resulted in skipping meals or eating junk food. In affordable food places, their freedom of choice regarding edible food and control over levels of sensory stimulation privacy seemed to tend to be more limited. Studying foodways may be a useful
approach to better understand the associations between objective health outcomes and access to supermarkets and restaurants.

Second, the findings on how autism-related characteristics fundamentally affect the way the autistic participants experience the food environment due to their sensitivity to environmental stimuli imply that environmental psychologists might need to consider autistic traits as a person-based variable, along with other person-based variables such as gender, personality, and stage in life course that can influence how human responds to and acts with regard to the physical environment (Winkel, Saegert, & Evans, 2009). Though the inclusion of autistic traits as a person-based variable has not been established in other fields yet either, the inclusion might be particularly important in the field of environmental psychology because the field studies the interaction between human and environment: A person perceives the physical environment through direct experience of looking, listening, touching, smelling, and tasting; autistic individuals respond to stimulus information from their environment differently than do others, because of their atypical sensory integration process, and they have low or high thresholds for certain sensory stimuli. Understanding autistic traits as a person-based variable is important also because autistic traits seem to be related to other more traditional person-based variables (i.e., gender, personality, and stage in life course). With respect to gender, boys are approximately four to five times more commonly diagnosed with autism than girls (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, 2014). Self-identified gender being neither male nor female has been reported to be more common among individuals with autism diagnoses (Van Schalkwyk, Klingensmith, & Volkmar, 2015), which is in line with the gender variance of my participants with formal autism diagnoses. Personality variables that have been used by environmental psychologists include traditional personality
dimensions such as the Big Five (i.e., openness (to experience), conscientiousness, extraversion, agreeableness, and neuroticism) and locus of control (internal versus external) (Gifford, 2014). Autistic traits have been found to be negatively related to extroversion and positively related to neuroticism (Austin, 2005; Wakabayashi, Baron-Cohen, & Wheelwright, 2006). Adults who are diagnosed with Asperger’s syndrome have externalized locus of control (Soderstrom, Rastam, & Gillberg, 2002).

Third, as a participatory study, whose goal is to contribute to improving quality of life of autistic adults, this study has implications for providers of restaurants, cafeterias, and grocery stores, which they find challenging. Participants’ responses taught me that an autism-friendly food environment is an environment where they can control the levels of social interaction and sensory stimulation, which can be overwhelming but should not be completely absent. By providing more booths or corners, or just tables against the walls or partitions, a food environment may accommodate such needs. Buffet-style restaurants and cafeterias, which were many participants’ favorite eating-out places, also may be helpful for autistic adults. In such places, autistic individuals, who tend to dislike both different foods touching each other and social chit-chat, can choose foods they want and put them in a plate or plates in their preferred way without much interaction with service staff. In self-service places, autistic individuals who feel suddenly extremely hungry can also immediately eat without waiting. While providing variety of food that include various allergen-free options and vegetarian options is important, providing at least a few staple food that do not constantly change is also important for some autistic people who know their ‘safe’ foods that they can rely on. Ventilation systems should successfully exhaust smells and small particles from cooking to maintain fresh air because autistic individuals tend to be very sensitive to smells. For those who need to take out food
because of an overwhelming eating place, taking out should not be discouraged. Food environments with extended hours is desirable because autistic individuals prefer to avoid busy hours that are noisy and crowded, and do not necessarily feel hungry when other people do; autistic individuals also might need to eat breakfast and dinner as well as lunch at work or at school because cooking a meal is challenging to them due to their reduced executive functions, while eating breakfast is important for their executive functions. Vending machines with high quality, healthy food options are desirable. With respect to grocery stores, providing an environment where unnecessary social interaction between customers and store staff can be minimized seems to be important because autistic adults tend to feel communicating with staff (e.g., asking questions and being asked) while dealing with overstimulating store very challenging. A more clear and self-exploratory store layout and aisle labeling may help shoppers be less confused and more independent; though a confusing layout may result in more purchases by making shopping time longer and leading to more impulse purchases, shopping satisfaction may decrease, especially if the shopper is autistic, because some autistic individuals have both problems with recognizing places due to topographic agnosia (or place blindness) (Lawton, 2007) and sensory sensitivity issues. For autistic individuals who feel extremely hungry when they have arrived in a supermarket, visibly displayed small food items near a cashier for a few items near the entrance would be helpful. Many autistic individuals might want to use self-service check-out counters because they often do not like social interaction with cashers. At least some of them should not have sound or light that may be too overwhelming to autistic people who are very sensitive to those stimuli. Food departments that sell items that have smells, such as sea-food and meat, might need to be displayed in glassed showcases and provided with air exhaust. Throughout food environments, unnecessarily too bright lighting that may cause
discomfort needs to be avoided. Provision of additional features for an autism-friendly food environment may also generally benefit and attract neurotypicals; for example, a confusing layout of a grocery store afflicts not only autistic individuals but also almost everybody including the elderly, people with perceptual limitations, and visitors to the area.

Fourth, the findings on food aversions of many autistic participants should let those who interact with them know that the issue is very serious to autistic individuals. Most participants had aversions to certain foods either for sensory reasons, ethical reasons or health reasons, such as indigestion and constipation. Respecting someone’s aversions to certain foods may be a starting point of creating an autism-friendly food environment. Because of food aversions, autistic individuals tend to have very limited food choices and being on another restricted diet may not be easy even when a person has sensitivities to common food substances, such as gluten or casein. Imposing certain diets onto an autistic person who has many food aversions (and does not have actual sensitivities to what those diets exclude) would only result in more stress and social isolation, which, in turn, would have deleterious effects on executive functions.

Fifth, autistic adults may benefit from this study in several aspects. First, they can see that their voices are valued and important in deepening our understanding of environments for them, and in turn, contribute to creating better environments for them. Considering that Mastermind was surprised to hear that his voice is important, it is likely that there are still many autistic people who consider their voices are not heard, although some autistic participants who preferred that I use their actual first and last names instead of disguising their identities participated in this research partly for a self-advocacy purpose. Given that asking for changes or help is difficult for many autistic people when they experience discomfort, participating in a study for a self-advocacy purpose is a useful way to improve their quality of life. Autistic adults can also learn
about some successful coping strategies used by participants of this study and some names or types of food environments that the participants like or dislike for various reasons. I also hope autistic individuals may see some value in the participation process itself that seeks to understand their lived experiences of autism. In addition to enjoying the process of participating in revising the research materials, Mastermind naturally experienced several everyday activities for the first time while he was spending time with me in a safe environment. His mother was inspired by my research and suggested he and I go grocery shopping to buy a few items. For Tony, who is socially isolated and wants to meet “the others” like him, I shared some information about where he may find them, such as an autism blog directory name and local autism support groups. He said he enjoyed the research participation and asked me to let him know about other research participation opportunities.

**Suggestions for Future Research**

Primary aims of exploratory research are to examine the feasibility of more extensive future research and to determine research methods to be used in future research. The findings of this exploratory research showed that a deeper understanding of foodways offers tremendous potential for understanding how autistic people negotiate and navigate their food environments. More extensive future research on foodways of autistic adults is necessary for more definitive answers to the research questions raised in this study. First, I suggest future research use a community-based participatory research approach, which involves individuals from the autism community at the collegiate level of participation during the entire research processes. This approach may more completely address their issues and develop clear research materials. This current study employed a limited participatory approach while attempting to address issues relevant to the autism community and develop survey and interview materials that are clear to
participants on the autism spectrum. Although I involved several individuals from the community while developing this research, some participants critiqued it, in that I did not thoroughly cover critical issues such as executive functions and social situations that revolve around food. There were also some questions that were unclear to the respondents. For example, the survey question about the experience of being on a restricted diet might have been interpreted in various ways by autistic participants, who tend to use and understand language more literally than non-autistic people.

Future research would also further investigate foodways of autistic adults by involving more sources of data such as a detailed analysis of photovoice (C. Wang & Burris, 1997) and blogs on lived experience of autistic individuals; more face-to-face interviews with autistic individuals who prefer that mode of interview, including walk-along interviews (Carpiano, 2009) with a video field research approach (Chapin & Turan, 2006; Harris, 2016). Interviews with spouses or partners of autistic adults might be informative as well, particularly regarding autistic males’ foodways, which could not be fully explored in this study due to lack of their participation. Future research that examines neurotypical participants’ foodways would allow the researcher to clearly identify what is related to autism and what is a more general issue.

On the other hand, given that the idea of autism is socially constructed (Nadesan, 2005), including autistic individuals—whether they are diagnosed or not—with different cultural backgrounds, especially with different understandings of autism may be a way to deepen our understanding of food environments for autistic individuals. Currently, research on understandings of autism in different culture is scant (Kapp, 2011). Oriental medicine’s understanding of human differences and ways to maintain health may help us overcome the dichotomy of pro-cure and anti-cure agendas and create health-promotive environments. I hope
that research collaborations between researchers from oriental medicine, conventional medicine, western alternative medicine, environmental psychology and autistic individuals in the future might open a new direction to understand health-promotive environments for autistic people.
APPENDICES
Appendix A

Recruitment Script for In-person Approach

Hello, my name is Jungja Park Cardoso and I am a Ph.D. student in environmental psychology at the Graduate Center of the City University of New York. What brings you here? (If the potential participant identifies himself or herself as an adult on the autism spectrum or the parent of an adult on the autism spectrum, I introduce my research). I am conducting my doctoral research on how adults on the autism spectrum with different understandings of autism negotiate and navigate the food environment. I’m particularly interested in learning about how certain environmental settings and situations are considered problematic or supportive in relation to everyday foodways - the beliefs and practices involved in growing food, going grocery shopping, cooking and eating food.

The research consists of two phases: 1) Online Survey and 2) Online Interview or offline interview.

Would you be interested in learning more about my research? If so, please give me your email address or email me at jpark1@gradcenter.cuny.edu or visit https://survey.gc.cuny.edu/s?s=XXXX for more detail about my research (I will provide the potential participants with a memo with my contact info and survey web address).

Your participation will contribute to a greater understanding of a food environment that is friendly to adults on the autism spectrum. All information that is collected about you will be kept confidential. Unless you specifically ask me to, I will never use any details that can be used to identify you in any written or verbal reports. Participants will be entered into a raffle to win one of twenty $25 e-Gift Cards. Once I have completed my study, I will share an electronic copy of my research findings with research participants.

If you would like to take the survey offline instead and would like to participate in the interview, you can do that. When I have an interview with you, I’ll ask you survey questions before we start the interview. Here is the Research Participant Information Sheet. Please carefully read it and let me know if you’re willing to give me your email address to communication with me to make an arrangement for the interview.

This study has been reviewed and approved by the Graduate Center of the City University of New York Institutional Review Board (IRB).
Appendix B

Recruitment Website Posting

Research on foodways and the food environment of adults on the autism spectrum

Are you (or is your child) an adult on the autism spectrum? Would you like to have your voice heard in research?

If so, I would like to invite you to participate in a study on foodways and the food environment of adults on the autism spectrum!

My name is Jungja Park Cardoso and I am a Ph.D. student in environmental psychology at the Graduate Center of the City University of New York. I am conducting my doctoral research on how adults on the autism spectrum with different understandings of autism negotiate and navigate the food environment. I’m particularly interested in learning about how certain environmental settings and situations are considered problematic or supportive in relation to everyday foodways - the beliefs and practices involved in growing food, going grocery shopping, cooking and eating food.

The research consists of two phases:

1) Online Survey and
2) Online Interview or offline Interview.

Your participation will contribute to a greater understanding of a food environment that is friendly to adults on the autism spectrum. All information that is collected about you will be kept confidential. Unless you specifically ask me to, I will never use any details that can be used to identify you in any written or verbal reports. Participants will be entered into a raffle to win one of twenty $25 e-Gift Cards. Once I have completed my study, I will share an electronic copy of my research findings with research participants.

If you (or someone you know) are interested in learning more about this study, please contact me:

Jungja Park Cardoso

E-mail: JPark1@gradcenter.cuny.edu

Or visit https://survey.gc.cuny.edu/s?s=3797

This study has been reviewed and approved by the Graduate Center of the City University of New York Institutional Review Board (IRB).
Appendix C

Informed Consent Form for Adults on the Autism Spectrum and the Parents

RESEARCH PARTICIPANT INFORMATION SHEET

City University of New York
The Graduate Center
Environmental Psychology

Title of Research Study: Negotiating and navigating the food environment: Foodways of adults on the autism spectrum

Principal Investigator: Jungja Park Cardoso, M.Phil.
Ph.D Candidate

Thanks so much for visiting this page to learn more about my research! My research is on how adults on the autism spectrum with different conceptions of autism negotiate and navigate the food environment. I’m particularly interested in learning about how certain environmental settings and situations are considered problematic or supportive in relation to everyday foodways - the beliefs and practices involved in eating food, going grocery shopping, growing food, and cooking. If you are an adult on the autism spectrum and/or the parent of an adult on the spectrum, you’re eligible to participate in this research. Your participation will contribute to a greater understanding of a food environment that is friendly to adults on the spectrum. All information that is collected from you will be kept confidential. Unless you specifically ask me to, I will never use any details that can be used to identify you in any written or verbal reports. Once I have completed my study, I will share an electronic copy of my research findings with research participants.

The research consists of two phases: 1) online survey and 2) online or offline interview. The second phase of this research (the interview) is completely optional. If you choose to complete phase one (the survey), you are under no obligation to complete phase two (the interview).
Participants will be entered into a raffle to win one of twenty $25 e-Gift Cards. If you participate in both phases, your chance of winning will be doubled. The raffle will be drawn as soon as all data is collected.

**Phase 1: Online Survey**

The survey consists of the following sections:

- Autism spectrum diagnosis history
- Ritvo Autism and Asperger Diagnostic Scale -14 (RAADS-14) (Eriksson, Andersen, & Bejerot, 2013)
- Conceptions of autism
- Quality of life
- Foodways
- Demographic information

The survey will take approximately 20-30 minutes. You will be given an option to save your progress so that you may continue the survey later. Your participation in this research is voluntary. You can quit the survey and withdraw from the study at any time. The survey is anonymous. But, if you are willing to be contacted for an interview, you will be asked to provide your email address. The interview will constitute the second phase of this research. If you choose to participate in the interview as well, the data from the survey will be linked to the data from the interview and will no longer be anonymous. If you would like to be entered into the raffle but do NOT want to be contacted for the interview, you'll be asked to provide your email address at a page that is not connected to your survey answers.

To protect your privacy, I will not record your Internet Protocol (IP) address. I will also use Secure Sockets Layer (SSL) encryption (see "https" in the address bar) to make sure your survey won't be seen by any third parties. However, no guarantees can be made regarding the interception of data sent via the Internet by any third parties.

**Phase 2: Interview (Optional)**

You may choose to have an online or an offline interview, whichever you feel more comfortable with. During the interview, I will mostly ask you about how certain
environmental settings and situations are considered problematic or supportive in relation to everyday foodways. The interview will take place once or over the course of up to a month. The time of your participation will vary, depending on how often and how long you take breaks during the interview. Please expect to have the interview for 1 to 2 hours. A follow-up might take place sometime after the interview.

**Choice 1: Offline Interview**
If you live in or around New York City and prefer an interview in person, you and I will get together at a mutually convenient time and place to have an interview. Some parts of the interview may be done while I walk along with you in environments that are familiar to you. Our conversations will be recorded with my digital voice recorder for accuracy of transcribed interview contents.
If you are the parent of an adult on the autism spectrum and would like to participate in the interview with your son or daughter on the spectrum, please email me.

**Choice 2: Online Interview**
If you do not live in or around New York City or prefer doing an online interview, you may participate in the online interview. Three types of online interviews are available in this study for your convenience. Please feel free to choose from an e-mail interview, Instant Messaging, or online video (or voice only) interview. If you choose to have an online video (or voice only) interview, our conversations will be recorded with my digital voice recorder for accuracy of transcribed interview contents.

If you have any questions, comments or concerns about the research, please email me, Jungja Park Cardoso, at jpark1@gradcenter.cuny.edu. If you have questions about your rights as a research participant, or you have comments or concerns that you would like to discuss with someone other than me, please call the CUNY Research Compliance Administrator at 646-774-8918. This study has been reviewed and approved by the Institutional Review Board (IRB) of the City University of New York. (IRB protocol #: 2015-0724)

You may save (and/or print) a copy of this form for your records.

As mentioned, if you are an adult on the autism spectrum and/or the parent of an adult on the spectrum, you're eligible to participate in this research.
Do you agree to participate in the online survey, the first phase of this research? (If you provide me with your email address at the end of the survey, a separate consent form for the interview, the second phase of this research, will be obtained before the interview)

- [ ] I agree
- [ ] I do not agree

If you do not agree to participate in the online survey, please stop here. Thank you.
Thank you for agreeing to participate in the survey!

As mentioned in the research Participant Information Sheet, this survey asks about your relationships with autism, conceptions of autism, quality of life, foodways and demographic information. Answers for this survey will help me know about participants before I have in-depth interviews, which will focus on how certain environmental settings and situations are considered problematic or supportive in relation to everyday foodways.

Several questions, mostly those related to the autism spectrum diagnosis, are required. The reason is because this online survey is designed with skip logic. Questions that are irrelevant to you will be automatically skipped based on your checking of certain answers. Required questions are marked with asterisks (*).

You can save answers and resume later.

Q1.: Do you consider yourself to be on the autism spectrum? *

☐ Yes  ☐ No

Relationships with autism

Q2.: Have you ever been formally diagnosed with an autism spectrum condition by a professional? *

☐ Yes  ☐ No

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question

Q3.: Why do you consider yourself to be on the autism spectrum?
Q4.: Why do you consider yourself to be on the autism spectrum other than because you have been diagnosed with an autism spectrum condition?

Q5.: Why do you consider yourself not to be on the autism spectrum though you have been diagnosed with an autism spectrum condition?
Q6.: Which autism spectrum diagnosis did you most recently receive?

- Level 1 Autism Spectrum Disorder
- Level 2 Autism Spectrum Disorder
- Level 3 Autism Spectrum Disorder
- Autistic Disorder
- Asperger's Disorder
- Rett's Disorder
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)
- Not applicable
- I don't know
- Other (please specify)

Q7.: How old were you when you were most recently diagnosed?

I was ____ years old.

Q8.: Were you diagnosed with a different autism spectrum condition prior to your current autism spectrum diagnosis? *

- Yes
- No

Q9.: What prior autism spectrum diagnoses did you receive? How old were you when you received each of the diagnoses?
RAADS-14

The Ritvo Autism and Asperger Diagnostic Scale -14 (RAADS-14) is a short version of the Ritvo Autism and Asperger Diagnostic Scale-Revised (RAADS-R). Your answers in this section will help me reconfirm how much you're likely or unlikely to be on the autism spectrum. Having this measure will also help me compare my research findings to other researchers'. I apologize in advance if you feel that this survey is repetitive with this measure or that the items of the measure sound a little judgmental. You'll be given the option to say about the RAADS-14 questions at the end of this section.

Q10.: Please choose one of the following alternatives:

- This is true or describes me now and when I was young.
- This was true or describes me only now (refers to skills acquired).
- This was true only when I was young (16 years or younger).
- This was never true and never described me.

Please answer the questions according to what is true for you. Check only one column per statement.

<table>
<thead>
<tr>
<th>Some life experiences and personality characteristics that may apply to you</th>
<th>True now and when I was young</th>
<th>True only now</th>
<th>True only when I was younger than 16</th>
<th>Never true</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is difficult for me to understand how other people are feeling when we are talking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some ordinary textures that do not bother others feel very offensive when they touch my skin</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is very difficult for me to work and function in groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is difficult to figure out what other people expect of me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I often don’t know how to act in social situations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I can chat and make small talk with people</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When I feel overwhelmed by my senses, I have to isolate myself to shut them down</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q11.: Please answer the questions according to what is true for you. Check only one column per statement.

<table>
<thead>
<tr>
<th>Some life experiences and personality characteristics that may apply to you</th>
<th>True now and when I was young</th>
<th>True only now</th>
<th>True only when I was younger than 16</th>
<th>Never true</th>
</tr>
</thead>
<tbody>
<tr>
<td>How to make friends and socialize is a mystery to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When talking to someone, I have a hard time telling when it is my turn to talk or to listen</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes I have to cover my ears to block out painful noises (like vacuum cleaners or people talking too much or too loudly)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It can be very hard to read someone's face, hand, and body movements when we are talking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I focus on details rather than the overall idea</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take things too literally, so I often miss what people are trying to say</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get extremely upset when the way I like to do things is suddenly changed</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Q12.: Is there anything you want to say about the RAADS-14 questions?
Q13.: Do you have children? *

☐ Yes  ☐ No

Note: if you have answered/chosen item [2] in question 13., skip the following question

Q14.: How many children do you have?

☐ One  ☐ Two  ☐ Three  ☐ Four
☐ Other (please specify)

If you have chosen "other", please specify:

Q15.: Do you consider (any of) your child(ren) to be on the autism spectrum? *

☐ Yes  ☐ No

The following questions are about your child on the autism spectrum. If you have more than one child on the spectrum, please answer regarding your child who needs the autism-friendly environment most.

Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [2] in question 15., skip the following question

Q16.: Is your child at least 18 years old? *

☐ Yes  ☐ No

Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [2] in question 15., skip the following question

Q17.: Has your child ever been formally diagnosed with an autism spectrum condition by a professional? *

☐ Yes  ☐ No

Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 15., skip the following question
Note: if you have answered/chosen item [1] in question 15. AND answered/chosen item [1] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Q18.: Have any of your children ever been formally diagnosed with an autism spectrum condition by a professional? *

☐ Yes  ☐ No

Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [2] in question 15., skip the following question
Note: if you have answered/chosen item [1] in question 17. AND answered/chosen item [2] in question 15., skip the following question
Note: if you have answered/chosen item [1] in question 15. AND answered/chosen item [1] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 18. AND answered/chosen item [2] in question 15., skip the following question

Q19.: Why do you consider your child to be on the autism spectrum?

Q20.: Why do you consider your child to be on the autism spectrum other than because your child has been diagnosed with an autism spectrum condition?
Q21.: Why do you consider your child(ren) not to be on the autism spectrum though your child(ren) has been diagnosed with an autism spectrum condition?
Q22.: Which autism spectrum diagnosis did your child most recently receive?

- Level 1 Autism Spectrum Disorder
- Level 2 Autism Spectrum Disorder
- Level 3 Autism Spectrum Disorder
- Autistic Disorder
- Asperger's Disorder
- Rett's Disorder
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)
- Not applicable
- I don't know
- Other (please specify)

If you have chosen "other", please specify:

Q23.: How old was your child when he or she was diagnosed?

My child was ______ years old.

Q24.: Was your child diagnosed with a different autism spectrum condition prior to his or her current autism spectrum diagnosis? *

- Yes
- No
Q25.: What prior autism spectrum diagnoses did your child receive? How old was your child when he or she received each of the diagnosis?

Q26.: Is the child at least 18 years old? *

☐ Yes  ☐ No

Conceptions of Autism

Q27.: For each item below, please indicate how strongly you agree or disagree with that statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>I don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism is a way of being</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Autism is a disorder</td>
<td></td>
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<tr>
<td>Autism is a part of an individual's identity</td>
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<tr>
<td>Autism needs to be cured</td>
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<tr>
<td>Autism needs to be celebrated</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Autism needs to be treated</td>
<td></td>
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<tr>
<td>Autism is a gift</td>
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</tr>
</tbody>
</table>
Q28.: For each item below, please indicate how completely the following statements are true.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Mostly</th>
<th>Completely</th>
<th>I don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism is a disability</td>
<td></td>
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<tr>
<td>Autism is a natural human variation</td>
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<tr>
<td>Autism is a genetic condition</td>
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<tr>
<td>Environmental pollution causes autism</td>
<td></td>
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<tr>
<td>Autism is a brain condition</td>
<td></td>
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<tr>
<td>Autism is a whole body condition</td>
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<tr>
<td>Autism is hardwired</td>
<td></td>
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<tr>
<td>Autism is a biomedical condition</td>
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</tbody>
</table>

Q29.: What is autism in your own words?


Q30.: Some people say that certain diets "help with autism." What do you think?


### About Your Quality of Life

*Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question*

**Q31.: How satisfied are you with the following aspects of your quality of life?**

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Strongly dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Satisfied</th>
<th>Strongly satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical well-being</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Emotional well-being</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal relations</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Social inclusion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Personal growth</td>
<td></td>
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<tr>
<td>Economic well-being</td>
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<tr>
<td>Self-determination</td>
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<tr>
<td>Individual rights</td>
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<td></td>
<td></td>
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</tbody>
</table>

*Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question*

**Q32.: How important are the following aspects of your quality of life?**

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Very important</th>
<th>Important</th>
<th>Moderately important</th>
<th>Slightly important</th>
<th>Not important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical well-being</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional well-being</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interpersonal relations</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Social inclusion</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Personal growth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Economic well-being</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-determination</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Individual rights</td>
<td></td>
<td></td>
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</tbody>
</table>


About Your Foodways

This section will ask about your foodways. Foodways are the beliefs and practices involved in eating food, going grocery shopping, growing food, and cooking.

Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question

Q35.: Are there foods you prefer not to eat? *

☐ Yes  ☐ No

Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question
Note: if you have answered/chosen item [2] in question 35., skip the following question

Q36.: If there are some foods you prefer not to eat, what are those foods? (Check all that apply)

☐ Fruits and berries  ☐ Greens  ☐ Legumes  ☐ Tubers
☐ Grains  ☐ Poultry  ☐ Fish  ☐ Seafood (non-fish)
☐ Beef  ☐ Pork  ☐ Eggs  ☐ Dairy
☐ Nuts  ☐ Not applicable  ☐ Other (please specify)

If you have chosen "other", please specify:


Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question
Note: if you have answered/chosen item [2] in question 35., skip the following question

Q37.: Why do you prefer not to eat those types of food?
Q38.: Have you ever been on any restricted diets? *

- [ ] Yes
- [ ] No

Q39.: What has been challenging maintaining the diet? (Check all that apply)

<table>
<thead>
<tr>
<th>Diet Style</th>
<th>Hassles</th>
<th>Time consuming</th>
<th>Socially isolating</th>
<th>Expensive</th>
<th>Difficulty in finding places to eat out</th>
<th>Didn't improve health</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organic diet</td>
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<tr>
<td>Vegetarian diet</td>
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<tr>
<td>Pescetarian diet</td>
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<td>Vegan diet</td>
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<td>Raw vegan diet</td>
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<td>Gluten-free diet</td>
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<td>Dairy-free diet</td>
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<td>Paleo diet</td>
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<td>Specific Carbohydrate diet</td>
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<tr>
<td>Gut and psychology syndrome diet</td>
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<td>Other</td>
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<td></td>
<td></td>
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</tbody>
</table>
Q41: If you have chosen "other", please specify.

Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question

Q40.: Do you like grocery shopping?

- Yes, I love it
- Yes, I like it
- No, I don't like it
- No, I hate it
- Other (please specify)

If you have chosen "other", please specify:

Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question

Q41.: Do you go grocery shopping? *

- Yes
- No
Q42.: How often do you shop groceries in the following settings?

<table>
<thead>
<tr>
<th></th>
<th>More than 4 times a week or everyday</th>
<th>2-3 times a week</th>
<th>Once a week</th>
<th>2-3 times a month</th>
<th>Once a month or less</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supermarkets</td>
<td></td>
<td></td>
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<tr>
<td>Farmer's market</td>
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<tr>
<td>Corner grocery stores</td>
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<tr>
<td>Food carts</td>
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<tr>
<td>Health-food store</td>
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<tr>
<td>Food co-op</td>
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<tr>
<td>Online grocer</td>
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<tr>
<td>Community Supported Agriculture (CSA)</td>
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<tr>
<td>Other</td>
<td></td>
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</tr>
</tbody>
</table>

Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question

Q45: If you have chosen "other", please specify.
Q43.: What are the reasons that you don't go grocery shopping? (Check all that apply)

[ ] Grocery shopping is too stressful
[ ] I can only go when someone helps me
[ ] I don't cook
[ ] I live in a place where meals are provided
[ ] Other (please specify)

If you have chosen "other", please specify: ____________________________

Q44.: What aspects of grocery stores make it hard for you to go grocery shopping? (Check all that apply)

[ ] Smell
[ ] Noise
[ ] Air quality
[ ] Lighting
[ ] Aesthetic quality
[ ] Store layout
[ ] Crowding
[ ] Location
[ ] Operation hours
[ ] Price
[ ] Variety of food
[ ] Other (please specify)

If you have chosen "other", please specify: ____________________________

Q45.: Which strategies do you use to cope with sensory challenges you face while grocery shopping? (Check all that apply)

[ ] I don't have sensory challenges while grocery shopping
[ ] Wearing ear plugs or noise cancellation ear phones
[ ] Wearing a hat
[ ] Wearing sunglasses
[ ] Wearing a mask
[ ] Shopping in the middle of night or at other odd times
[ ] Other (please specify)

If you have chosen "other", please specify: ____________________________
**Q46.: How often do you eat out in the following places?**

<table>
<thead>
<tr>
<th>Place</th>
<th>More than 4 times a week or everyday</th>
<th>2-3 times a week</th>
<th>Once a week</th>
<th>2-3 times a month</th>
<th>Once a month or less</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workplace or school cafeterias</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Restaurants</td>
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<tr>
<td>Prepared foods from delis</td>
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<tr>
<td>Fast-food outlets</td>
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<tr>
<td>At the office desk</td>
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<tr>
<td>Bars</td>
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<tr>
<td>Other</td>
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</tbody>
</table>

**Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question**

**Q50: If you have chosen "other", please specify.**

If you have chosen "other", please specify:

**Note: if you have answered/chosen item [2] in question 1. AND answered/chosen item [2] in question 2., skip the following question**

**Q47.: What aspects of eating out make it hard for you to comfortably eat? (Check all that apply)**

- [ ] Smell
- [ ] Noise
- [ ] Air quality
- [ ] Lighting
- [ ] Aesthetic quality
- [ ] Store layout
- [ ] Crowding
- [ ] Location
- [ ] Operation hours
- [ ] Price
- [ ] Variety of food
- [ ] Other (please specify)

If you have chosen "other", please specify:
Q48.: What are some strategies you use to cope with sensory challenges you face while eating out? (Check all that apply)

- [ ] I don't have sensory challenges while eating out
- [ ] Wearing ear plugs or noise cancellation ear phones
- [ ] Wearing a hat
- [ ] Wearing sunglasses
- [ ] Dining out at odd times
- [ ] Taking out food
- [ ] Bringing own food
- [ ] Other (please specify)

If you have chosen "other", please specify:

Q49.: Do you usually eat with others when you eat out?

- [ ] Yes
- [ ] No

Q50.: What are some challenges when eating out with others? (Check all that apply)

- [ ] Dietary restrictions
- [ ] I don't like places where others like to go
- [ ] Arranging to eat together is difficult
- [ ] I don't necessarily eat when others eat
- [ ] Having conversations during mealtime is difficult
- [ ] The sounds of other people eating bother me
- [ ] Other (please specify)

If you have chosen "other", please specify:

Q51.: Do you grow your own food at least in part?

- [ ] Yes
- [ ] No
Q52.: Do you usually prepare, assemble or cook a meal on your own?

☐ Yes  ☐ No

Q53.: What are some challenges when preparing, assembling or cooking? (Check all that apply)

☐ Cooking is dangerous  ☐ Meals are provided
☐ Time constraints  ☐ Expenses
☐ Lack of knowledge  ☐ Lack of an adequate place to cook in
☐ Smell from cooking  ☐ Other (please specify)

If you have chosen "other", please specify:

About Your Child's Foodways

This section will ask about your child's foodways. Foodways are the beliefs and practices involved in eating food, going grocery shopping, growing food, and cooking.

Q54.: Are there foods your child prefers not to eat? *

☐ Yes  ☐ No
Q55.: If there are some foods your child prefers not to eat, what are those foods? (Check all that apply)

- Fruits and berries
- Greens
- Legumes
- Tubers
- Grains
- Poultry
- Fish
- Seafood (non-fish)
- Beef
- Pork
- Eggs
- Dairy
- Nuts
- Not applicable
- Other (please specify)

If you have chosen "other", please specify:

[Blank space]

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question
Note: if you have answered/chosen item [2] in question 54., skip the following question

Q56.: Why does your child prefer not to eat those types of food?

[Blank space]

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question
Note: if you have answered/chosen item [2] in question 54., skip the following question

Q57.: Has your child ever been on any restricted diets? *

- Yes
- No
Q58.: What has been challenging maintaining the diet?  (Check all that apply)

<table>
<thead>
<tr>
<th>Diet Type</th>
<th>Hassles</th>
<th>Time consuming</th>
<th>Socially isolating</th>
<th>Expensive</th>
<th>Difficulty in finding places to eat out</th>
<th>Didn't improve health</th>
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<tbody>
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<td>Organic diet</td>
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<td>Vegetarian diet</td>
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<td>Pescetarian diet</td>
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<tr>
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<td>Raw vegan diet</td>
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<td>Gluten-free diet</td>
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<td>Dairy-free diet</td>
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<td>Paleo diet</td>
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<td>Specific Carbohydrate diet</td>
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<td>Gut and psychology syndrome diet</td>
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<td>Other</td>
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</tbody>
</table>
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question
Note: if you have answered/chosen item [2] in question 57., skip the following question

Q63: If you have chosen "other", please specify.

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question

Q59.: Does your child like grocery shopping?

- Yes, my child loves it
- Yes, my child likes it
- No, my child doesn't like it
- No, my child hates it
- Other (please specify)

If you have chosen "other", please specify:

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question

Q60.: Does your child go grocery shopping? *

- Yes
- No

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question
Note: if you have answered/chosen item [2] in question 60., skip the following question
Q61.: Where does your child usually shop groceries?

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question

Q62.: What are the reasons that your child doesn't go grocery shopping? (Check all that apply)

- Grocery shopping is too stressful
- My child can go only when someone helps
- My child doesn't cook
- My child lives in a place where meals are provided
- Other

If you have chosen "other", please specify:

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question

Q63.: What aspects of grocery stores make it hard for your child to do grocery shopping? (Check all that apply)

- Smell
- Noise
- Air quality
- Lighting
- Aesthetic quality
- Store layout
- Crowd density
- Location
- Operation hours
- Price
- Variety of food
- Other (please specify)

If you have chosen "other", please specify:

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question
Q64.: Which strategies does your child use to cope with sensory challenges faced while grocery shopping? (Check all that apply)

- [ ] My child does not have sensory challenges while grocery shopping
- [ ] Wearing ear plugs or noise cancellation ear phones
- [ ] Wearing a hat
- [ ] Wearing sunglasses
- [ ] Wearing a mask
- [ ] Shopping in the middle of night or at other odd times
- [ ] Other (please specify)

If you have chosen "other", please specify:

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question

Q65.: Where does your child usually eat out?

Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [2] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question

Q66.: What aspects of eating out make it hard for your child to comfortably eat? (Check all that apply)

- [ ] Smell
- [ ] Aesthetic quality
- [ ] Operation hours
- [ ] Noise
- [ ] Store layout
- [ ] Price
- [ ] Air quality
- [ ] Crowd density
- [ ] Variety of food
- [ ] Lighting
- [ ] Location
- [ ] Other (please specify)

If you have chosen "other", please specify:
Q67.: What are some strategies your child uses to cope with sensory challenges faced while eating out? (Check all that apply)

- My child does not have sensory challenges while eating out
- Wearing ear plugs or noise cancellation ear phones
- Wearing a hat
- Sunglasses
- Dining out
- At odd times
- Taking out food
- Bringing own food
- Other (please specify)

If you have chosen "other", please specify:

Q68.: Does your child usually eat with others when eating out?

- Yes
- No

Q69.: What are some challenges faced when eating out with others? (Check all that apply)

- Dietary restrictions
- Arranging to eat together is difficult
- Having conversations during mealtime is difficult
- My child doesn't like places where others like to go
- My child doesn't necessarily eat when others eat
- The sounds of other people eating bother my child
- Other (please specify)
Q70.: Does your child grow his or her own food at least in part?

☐ Yes  ☐ No

If you have chosen "other", please specify:

Q71.: Does your child usually prepare, assemble or cook a meal on his or her own?

☐ Yes  ☐ No

Q72.: What are some challenges your child faces when preparing, assembling or cooking a meal on his or her own? (Check all that apply)

☐ Cooking is dangerous  ☐ Meals are provided
☐ Time constraints  ☐ Expenses
☐ Lack of knowledge  ☐ Lack of an adequate place to cook in
☐ Smell from cooking  ☐ Other (please specify)

If you have chosen "other", please specify:
Demographic Information

I hope you will answer all the questions in this section, but you may choose to skip any questions that you do not wish to answer.

Q73.: What is your gender?

- [ ] Male  - [ ] Female  - [ ] Other

If you have chosen "other", please specify:

________________________

Q74.: What year were you born in?

I was born in

________________________

Q75.: What is your ethnicity?

________________________

Q76.: What is your marital status?

- [ ] Single  - [ ] Separated  - [ ] Married  - [ ] Divorced
- [ ] Living with partner  - [ ] Widowed  - [ ] Other (please specify)

If you have chosen "other", please specify:

________________________

Q77.: What is your employment status? (Check all that apply)

- [ ] Full-time student  - [ ] Part-time student
- [ ] Employed full-time/full-year  - [ ] Employed part-time
- [ ] Seeking employment  - [ ] Not seeking employment
- [ ] Retired  - [ ] Stay-at-home parent
- [ ] Not currently working due to disability  - [ ] Not currently working for reasons other than disability
- [ ] Involved in autism advocacy work  - [ ] Other (Please specify)
Q78.: What is the highest level of education you achieved?

- ☐ Less than high school
- ☐ GED (general equivalency diploma)
- ☐ High school
- ☐ Some college or university courses
- ☐ Associate's degree
- ☐ Bachelor's degree
- ☐ Some graduate school
- ☐ Master's degree
- ☐ Doctorate
- ☐ Other (please specify)

If you have chosen "other", please specify:

- ☐

Q79.: What country do you live in?

- ☐ United States
- ☐ United Kingdom
- ☐ Canada
- ☐ Australia
- ☐ Other (Please specify)

If you have chosen "other", please specify:

- ☐

Note: if you have answered/chosen item [2, 3, 4, 5] in question 79., skip the following question
Note: if you have answered/chosen none of the following items: [1, 2, 3, 4, 5] in question 79., skip the following question

Q80.: What U.S. region do you live in?

- ☐ Eastsouth
- ☐ Midwest
- ☐ Northeast
- ☐ West
- ☐ Westsouth

Q81.: Where do you live?

- ☐ Urban area
- ☐ Suburban area
- ☐ Small town
- ☐ Rural area

Note: if you have answered/chosen item [2, 3, 4, 5] in question 79., skip the following question
Note: if you have answered/chosen item [2, 3, 4] in question 81. OR answered/chosen item [1, 2, 4, 5] in question 80., skip the following question

Q82.: Do you live in New York City?

- ☐ Yes
- ☐ No
Q83.: What is your living arrangement?

- Living independently
- Living with parent(s)
- Living with child(ren)
- Living in a group quarter
- Other (please specify)

If you have chosen "other", please specify:

Q84.: What was your approximate personal annual income in US dollar before taxes during the past 12 months?

- Less than $25,000
- $25,000 to $49,999
- $50,000 to $74,999
- $75,000 to $99,999
- $100,000 or more
- Supported by family
- On public assistance
- I don't know
- Do not wish to say

Q85.: Are you a blogger? *

- Yes
- No

Note: if you have answered/chosen item [2] in question 85., skip the following question

Q86.: Do you blog about autism spectrum? *

- Yes, often
- Yes, but rarely
- No

Note: if you have answered/chosen item [2] in question 85., skip the following question
Note: if you have answered/chosen item [3] in question 86., skip the following question

Q87.: What is the title of your blog?
About your child

Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question

Q88.: What is your child's gender?

- Male
- Female
- Other

If you have chosen "other", please specify:

Q89.: What year was your child born in?

My child was born in

Q90.: What is your child's ethnicity?

Q91.: What is your child's marital status?

- Single
- Separated
- Married
- Divorced
- Living with partner
- Widowed
- Other (please specify)
Q92.: What is your child's employment status? (Check all that apply)

- [ ] Full-time student
- [ ] Employed full-time/full-year
- [ ] Seeking employment
- [ ] Retired
- [ ] Not currently working due to disability
- [ ] Involved in autism advocacy work
- [ ] Part-time student
- [ ] Employed part-time
- [ ] Not seeking employment
- [ ] Stay-at-home parent
- [ ] Not currently working for reasons other than disability
- [ ] Other (Please specify)

If you have chosen "other", please specify:

Q93.: What is the highest level of education your child achieved?

- [ ] Less than high school
- [ ] GED (general equivalency diploma)
- [ ] High school
- [ ] Some college or university courses
- [ ] Associate's degree
- [ ] Bachelor's degree
- [ ] Some graduate school
- [ ] Master's degree
- [ ] Doctorate degree
- [ ] Other (please specify)

If you have chosen "other", please specify:

Q94.: What country does your child live in?

- [ ] United States
- [ ] United Kingdom
- [ ] Canada
- [ ] Australia
- [ ] Other (Please specify)
Q95.: What U.S. region does your child live in?
- [ ] East south
- [ ] Midwest
- [ ] Northeast
- [ ] West
- [ ] Southwest

Q96.: Where does your child live?
- [ ] Urban area
- [ ] Suburban area
- [ ] Small town
- [ ] Rural area

Q97.: What is your child's living arrangement?
- [ ] Living independently
- [ ] Living with parent(s)
- [ ] Living with child(ren)
- [ ] Living in a group quarter
- [ ] Other (please specify)
Q98.: What was your child's approximate personal annual income in US dollar before taxes during the past 12 months?

- Less than $25,000
- $25,000 to $49,999
- $50,000 to $74,999
- $75,000 to $99,999
- $100,000 or more
- Supported by family
- On public assistance
- I don't know

Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 16., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question

Q99.: Is your child a blogger? *

- Yes
- No
- I don't know

Note: if you have answered/chosen item [2] in question 13., skip the following question
Note: if you have answered/chosen item [1] in question 2. AND answered/chosen item [1] in question 1., skip the following question
Note: if you have answered/chosen item [2] in question 15. AND answered/chosen item [2] in question 17., skip the following question
Note: if you have answered/chosen item [2] in question 26., skip the following question
Note: if you have answered/chosen item [2] in question 99., skip the following question
Note: if you have answered/chosen item [3] in question 99., skip the following question

Q100.: Does your child blog about autism spectrum?

- Yes, often
- Yes, but rarely
- No
- I don't know

Q101.: Is there anything you would like to add? Please feel free to critique this survey.
Q107: I would like to email you to set up an interview with you. If you are willing to be contacted, please provide me with your email address. If you previously provided your email address to save your answers and continue later, please provide it here again.

After completing this survey, you will be entered into a raffle to win one of twenty $25 e-Gift Cards. If you participate in the interview as well, your chance of winning will be doubled.

If you would like to be entered into the raffle but do NOT want to be contacted for the interview, please provide me with your email address after clicking the link at the next page. The link is not connected to your survey answers.
Appendix E

Interview Questions for Autistic Adults

Before we begin

Q1: Thank you for participating in this interview. What motivated you to participate?

Q2: Please briefly describe what your life was like until you were (self-)diagnosed with your current autism spectrum diagnosis. Why was a diagnosis sought? How did you feel when you were diagnosed with your current autism spectrum condition?

Q3: Please tell me more about your health-related quality of life. What are some of your health concerns? How have you been managing your health? What have been some challenges in managing your health? What has been helpful in managing your health?

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Eating outside the home

Q4: Tell me about your favorite place(s) to eat out at. Which aspects of the place do you like? Are there any challenges in getting there or being there? How do you manage your time to be there?

Q5: Tell me about your least favorite place(s) for eating out. What aspects of the place do you not like?

If you frequently eat out at certain places, tell me about your experiences. (Q6 – Q7)

Q6: Where do you frequently eat? What do you usually eat there? Do you have any complaints about the places? Do you have any complaints about the variety or quality of food served?

Q7: What are the underlying circumstances compelling you to eat out at the particular places?

Q8: If you don't regularly eat out, why is that the case?
Q9: Try to remember a recent time when you were very annoyed by some aspects of eating out. How did some of those aspects make it hard for you to comfortably eat there?

Q10: You indicated that you do X, Y, Z as your strategies you use to cope with sensory challenges while eating out. Can you tell me more about that, such as how you came up with the idea, whether you have any concern on using the strategies?

Q11: When you had to eat out where you felt uncomfortable, how did you deal with the situation to seek out comfort? Have you tried to have such environments changed? If so, did you face any difficulties in doing that? Tell me about some of the challenges you experienced when you made such efforts.

**Grocery Shopping**

Q12: Tell me about your favorite grocery shopping place(s). Which aspects of the place do you like? Are there any challenges in getting there or being there?

Q13: Tell me about your least favorite grocery shopping place(s). Which aspects of the place do you not like?

If you regularly shop groceries at certain places, describe your experiences. (Q14 – Q15)

Q14: Where do you regularly shop groceries? What do you usually buy there? Do you have any complaints about their grocery shopping settings? Do you have any complaints about the variety or quality of the items?

Q15: What circumstances compel you to shop at the particular place?

Q16: If you don't regularly go grocery shopping, why is that the case?

Q17: Try to remember a recent time when you were very annoyed by some aspects of a grocery store. How did some of those aspects make it hard for you to do grocery shopping there?
Q18: You indicated that you do X, Y, Z as your strategies you use to cope with sensory challenges while doing grocery shopping. Can you tell me more about that, such as how you came up with the idea, whether you have any concern on using the strategies?

Q19: What time do you typically go grocery shopping and why?

Q20: When you had to do grocery shopping where you felt uncomfortable, how did you deal with the situation to seek out comfort? Have you tried to have such environments changed? If so, did you face any difficulties in doing that? Tell me about some of the challenges you experienced when you made such efforts.

Eating habits

Q21: Have you ever been on any restricted diet, such as vegetarian diet, pescetarian diet, organic diet or gluten-free diet? If so, please tell me about that experience. How did you start the diet? What motivated you to be on the diet? How long have you been on the diet? What has been challenging maintaining the diet? What have you successfully done in maintaining the diet?

If you are no longer on the diet, what are the reasons?

Q22: If you have never been on a restricted diet, what are the reasons?

Growing food

Q23: Have you ever grown your own food at least in part? If so, please describe that experience. How did you start growing your own food? What have you grown? Where have you grown? What motivated you to grow food? How long did you grow or have you been growing food? What have been some challenges while growing your food? What have you successfully done in maintaining the practice? If you no longer grow, what are the reasons?

Q24: If you have never grown your own food, what are the reasons?
Cooking

Q25: If you regularly cook on your own, tell me about your cooking. (How often do you cook? How many hours do you usually spend cooking per week? What do you typically cook and why? What have been some challenges while cooking?)

Q26: If you don't regularly cook, what are the reasons?

Q27: Is there anything you would like to add?
Appendix F

A List of Lydia’s Reasons to Consider *Themself* on the Autism Spectrum

Like many (but of course, not all) autistic people, I...

- Keep an erratic sleeping schedule, and am often nocturnal by both instinct and preference.

- Absolutely suck at executive functioning, which involves planning tasks, prioritizing tasks, initiating tasks, following through on tasks, meeting deadlines, organizing complex multi-step tasks, etc.

- Have very uneven skills academically, but present as conventionally ‘gifted.’ I functioned really, really well academically from K - 12, and then when I went to college, a lot of coping skills died. I developed some stuff, sure, but I know some stuff went straight out the window too, because huge changes, and also almost total lack of structure/scaffolding. (‘Now you're an adult, and you must be totally independent, and if you can't do that, too bad f u.’)

- Have hypersensitivities in all my senses (to noises, to smells, to tastes/textures, to touch/tactile sensation, to sights), which create both (1) sensory-seeking opportunities (I still rub a silk sleeve over my face – the very same one I've had since I was 3 and I'm now 22; also, tassels tassels tassels – yes I did in fact get a picture of myself inside the White House rubbing a tassel there all over my face) and (2) sensory-averse reactions (I am physically hurt by a lot of fluorescent lights; also, touching me lightly – not firmly – hurts).

- Tend to be more oblivious to surroundings/background information/implied knowledge. (This includes social knowledge – everyone else picks up on updates in people's
lives/doings much sooner than me; spatial knowledge – I can't recognize the same location in the dark versus in the light and also won't realize that objects/buildings/things exist unless they're explicitly pointed out to me; etc.)

- Frequently speak in circles, because I have extreme frustration when I believe the other person/people do not understand what I'm trying to communicate, so I attempt to rephrase (and can rephrase an infinite number of times, and go on for-fucking-ever with this unless stopped).

- Take great pleasure out of intense fascination with particular topic areas in ways that non-autistic people often do not.

- Relate to other people (and show that I care about them) specifically by seeking out gifts/activities/internet memes/other tangible or observable things that relate directly to their preferred interests or activities, but am often perceived as just creepy or weird by non-autistic people for doing this.

- Absolutely hate crowds and crowded locations because they're overwhelming and drain me of energy to start, do, or finish things, or just to concentrate, or just to survive.

- Occasionally lose the ability to produce oral speech even though I usually have the ability to use oral speech, especially when under extreme stress or exhaustion.

- Stim, like by using my tongue around my mouth in specific ways, or touching specific kinds of textures, or spinning in circles for a long time, or playing with water forever, including in fountains attached to government buildings, which results in being yelled at by security. (I stim when I'm anxious, when I'm bored, when I'm upset, when I'm happy, or when I'm excited. Also when I'm trying to communicate to another autistic person that I exist and am also autistic.)
- Tend to like certain types of structure and routine in ways that are not typical for non-autistic people. For example, whether playing with toy cars, Barbie or Bratz dolls, or Star Wars action figures, I would always line up all of the figures in specific orders/formations and three-dimensional spatial locations in my play area that almost never changed, which confused the hell out of all of my non-autistic friends/playmates. In another example, I'm also totally okay with eating literally *the exact same thing* for every meal for months on end, and this does not bother me.

- Extremely detail-oriented. For example, I write novels and do collaborative writing style roleplaying, and in both, I typically develop in immense detail aspects of constructed languages, socio-economic-political systems, cultural norms/histories, etc., as well as populating worlds (both those based on the real world and those that are totally sci-fi or fantasy settings) with hundreds or thousands of characters thought out in depth.

- Am highly attracted to and empathetic with animals (like cats and dogs) and fictional characters, which I feel are like real people and whom I care about in the same way I do as real people.

- Tend to take an incredibly long time to develop close friendships with people, and am constantly afraid of losing any of the friends that I have, because many of my closest friends in the past aren't my friends anymore (often but not always because they decided to not be my friend because I wasn't cool).

- Was severely bullied throughout school, both by other students and sometimes by teachers, for being an obvious weirdo. I'm usually perceived as out of touch, socially awkward, weird, abnormal, and just not with it when compared to a lot of my peers.
- Won't shut up when I really care about something, and am often perceived as arrogant, stuck-up, a know-it-all, full of myself, showing off, etc. even though I'm just trying to share information that I think the other person will care about or benefit from having.

- Don't really think in linguistic concepts/language. I think both visually and conceptually. So my thoughts happen in images (still pictures, moving videos, or four-dimensional fluid shapes/lines/fields/things-that-aren't-describable-but-I-probably-sound-like-I'm-under-the-influence-of-LSD-now) that represent concepts.

- Tend to be either really good intuitively at doing a thing, or really, really suck, and I keep sucking at it in the same pattern of sucking at it.

- Think systematically or in patterns. See above.

- Rely on scripts (entire encounters, types of situations, for behavior, or for what to say, etc.) for like 95% of my interactions involving other people, including other autistic people.

- Really, really like the feeling of pressure against my body. I often sit with legs/ankles crossed so I feel the pressure, or with my hand between both knees (I've learned that people assume I'm sexually touching myself in public if it's any higher up my leg). I like to sit so that my legs/ankles/feet can press against the legs of chairs or tables. I like to fall asleep with my arms tucked under my torso. Weighted blankets are awesome.

- Have some super awesome fine/gross motor skills, and some totally sucky fine/gross motor skills. For example, I have highly calligraphic scripted handwriting, and do black and white drawings in pen only (no pencil involved ever) with highly detailed cross-hatching. But then again, I've never reliably learned how to tie my shoes or do monkey bars or jump rope or hula hoop like most other kids I grew up around did.
- See squiggly bright lines and dots of various constantly-shifting colors whenever I'm conscious, which includes as I'm falling asleep too. (I'm sighted, which means I'm neither blind nor low-vision—not sure how/if blind or low-vision autistic people have these things.) Some people call them 'the floaters.'

- Have HIGHLY vivid, frequently narrative dreams, many of which I remember in incredibly detail. (Many of mine are also lucid.)

- Am synesthetic, meaning I experience many kinds of sensory input as *other* kinds of sensory input. Like, listening to music or even someone just talking, produces colors and shapes and yay.

- Will re-read or re-watch entire books or movies or tv shows—or specific scenes in them—that provoke deep, intense emotional reactions in me.

- Am highly empathetic to the point of over-empathizing. I may not always be able to process cognitively what I'm experiencing (see point below), but I am overwhelmed by the emotional responses of people around me—which includes things I read on the internet, because I'm experiencing them as the other person does. (Not in the way of, I know how it is to be them when I'm not them or don't have the same experiences, but in the way of, their anger settles in me, or their sadness settles in me, and I can't get rid of it.)

- Have trouble identifying/naming and separating/distinguishing all of my emotions or even bodily sensations.

- Am not antisocial. I'm an introvert, but I display a lot of outwardly extroverted-seeming traits, like talking to lots of people, going to events with lots of people, and having people

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34 The asterisks (*) were used by the participant possibly to emphasize the word, “other.”
over my place. Social interaction can be fun (or can suck massively, depending on who is involved and what they do to/around me), but it's draining. I need lots of extra time to recover. This is true even if the other people involved are also autistic.

- Desire to have some amount of environmental control that it seems like nonautistics tend not to have (either in general, or as intensely). Like, I get really anxious if other people touch or move my belongings/possessions, even if they're people I know really well and trust in general.

- Show that I trust others by opening up to them, emotionally and about my experiences.

- Typically have gravitated to be friends with people who were significantly older or significantly younger than me, and not my age-peers.

- Tend to do activities the exact same way all the time (like how I make pasta sauce or mint hot chocolate) even when I learn a better/easier way to do them.

- Don't care much about certain types of reputation/outward perceptions of me (like, buck the system; think whatever you want to think; fly that freak flag high; I'm here and queer get used to it; I once showed up to a White House event in a t-shirt while everyone else was in Western Business Attire; etc.) but am also extremely anxious about what others think of me vis a vis my character, my integrity, whether I'm worth being/having around. I'm sure there are many more, but another thing I have is anxiety around lists because I'm always wondering if I left something off the list (and usually do/did).

(This is totally unscientific and unempirical, but based on anecdotal observations from conversations with hundreds/thousands of other autistic people—both with formal diagnoses and without them, both speaking and nonspeaking, etc.—it just seems that all of these characteristics are *more common* in autistic people than they are in nonautistic people, and that the more of these kinds of characteristics someone has, the more likely

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35 The asterisks (*) were used by the participant possibly to emphasize the words, “more common.”
they are to be autistic. Obviously anyone who isn't autistic—which includes neurodivergent people who aren't autistic—could have any one or more of these characteristics too.)
Appendix G

Case Histories of Interview Participants

Online Interview Participants

Loren. Loren holds a non-binary gender identity. They was diagnosed with “either PDD-NOS or Asperger’s” in their early 20s. They has a doctoral degree and works full-time. They lives alone in an apartment in an urban area. They participated in this research because they has food aversions and experienced oppression against that: “I have serious food aversions related to being autistic, and I've had a bunch of experiences that I really hope no one else has to have.”

For them, growing up without an autism diagnosis “wasn’t fun”:

people thought I was oversensitive to things and was being weird on purpose, and also I got misdiagnosed with a lot of other stuff and medicated for it which really messed me up for a few years. [I was misdiagnosed with] ADHD, depression, bipolar disorder, OCD...

they thought I was out of touch with reality and gave me antipsychotics too.

They basically self-diagnosed before they was officially diagnosed with the autism condition: “It was kind of... underwhelming to be diagnosed, I guess, because I was already pretty sure.” They sought out a diagnosis in order to be sure of their being autistic, and to have the supplementary document in case they needs it.

Alyssa. Alyssa is an agender with a diagnosis of autistic disorder. They was diagnosed at the age of 19. They is a college student in a university located in an urban area and lives in a dormitory during the school year. During the summer, they stays at their family’s place. Because they seemed to be well connected to the adult autism community, I contacted them and asked if they could forward my recruitment flyers to their networks. Before forwarding my flyers, they
completed the online survey by *themself* first. Alyssa participated in this research because *they* thinks “feeding” *themself* is a concern for *them* and many other autistic adults:

Keeping myself fed is a concern of mine, because while it's financially not an issue – I have more than enough for that – and I generally have decent access to edible objects, making sure I remember to eat can be tricky, and by the time I remember I may well be past the point of making food or of eating out. I know this is a common issue for many autistic adults, and it sounds like your project is meant to be documenting some of the barriers which could help get them addressed, so it seemed like participating would be a pragmatic choice. Especially so since writing is how I organize my thoughts and I want to keep thinking about this kind of issue!

For most of Alyssa’s life, *their* parents “tried really hard to pass all [*their*] weird (autistic) traits off with ‘gifted kids are weird.’” While *they* was gifted, *they* experienced many challenges related to their autistic traits:

I got into trouble for organizational issues, for being surprisingly clumsy, for having terrible handwriting, for jumping and flapping my hands, for alternating between saying ALL THE WORDS and being really slow to answer questions with long pauses in the middle of my sentences, and just generally acting autistic.

Alyssa received an autism screening when *they* was a toddler. *Their* mother answered most of the questions with “no more than the rest of the family” type ideas, mostly comparing *them* to her father, who is also autistic. *Their* mother did not know at the time that he's autistic. *They* considers *their* grandfather to be autistic partly for talking very little: “[…] he pretty clearly is. He talks less than I do!” Unlike *their* mother, *their* father made some attempts to have *them* suppress the autistic traits such as using “non-word sounds” instead of words. When Alyssa
reached eight years old, they read an article about an autistic child “who sounded a lot like [them],” and asked their mother if they might be autistic. But their mother ‘Strongly disagreed “in a way that led [them] to believe that autism was not a good thing.” Thus they “kept quiet about it” for a while after that. In 5th, 6th, and 7th grades, they was in “a lunch group sort of thing” with mostly special education students though they officially “wasn’t anything yet.” “Eventually (late middle school? Early high school?),” they met an autistic student, who suggested they is autistic, too: “I met Lydia Brown at MIT Splash, and she36 kind of informed me that I am autistic.” They “didn't exactly believe” what Lydia told them at the time, but meeting a person who they knew to be autistic for the first in person was an important part of “the lead-up to diagnosis.” In 11th grade, they first had a teacher type person who suggested that they might be autistic. By then, it was “pretty much accepted that [they] was” autistic: “My friends at the time were a bit surprised … that I wasn't already diagnosed. They apparently thought it was pretty obvious that I'm autistic.” But they was not likely to get a diagnosis in high school because they “wasn't willing to put much effort into pursuing it at the time” and because their parents were “even less interested.” It wasn't until their sophomore year of college that Alyssa finally decided to pursue a diagnosis. At that point, they was self-diagnosed and told others about that: “I was pretty sure I was autistic, and I had started stating myself to be so.” Since they had access to diagnostic services, they decided to try a diagnosis, and received one:

Shortest interview ever. (It was with the therapist I'd been seeing most of the year.) It was about 20 minutes with the DSM, mostly spent hashing out which autistic spectrum diagnosis fit best. Also, she totally said right out that I knew more about autism than she did. Good times.

36 Lydia’s preferred pronoun is they/them/their.
Samantha. Samantha is a mid-50s female with a diagnosis of autism spectrum disorder. The functional levels for her ‘social communication’ and ‘restricted, repetitive behaviors’ are both Level 1. She was originally diagnosed with Asperger’s disorder in her mid-30s in 1995, which is one year after Asperger’s was included in DSM-IV. She works as a senior engineer in a research and development (R&D) department at a medical device company. She volunteers for Autism Speaks and helps sign up autistic engineers for jobs in her company online. Her company is “very big on [volunteering for Autism Speaks].” She participated in my research because she feels she has a moral obligation to speak for non-verbal autistic individuals, and wanted to help me:

I am communitive [sic] and as such I have a moral obligation to speak for those who are not. Also I am logical and therefore may express myself for those that cannot. I am also a senior R&D engineer so I understand what it is to have to do thesis research and want to help you. I mentor interns on their thesis work a lot.

Samantha was one of the few online survey autistic participants who think Autism needs to be cured. She lives with her husband in a suburban area. She loves her pets very much to the point she loves them more than her stepchildren although she “realizes that it is poor form to say so”; her anger and loneliness are mitigated by her pets.

As a child, she received special needs education. Her school district placed all students with special needs together, and as long as they were “manageable (no harm or violence)” let them do what they wanted. It is called Montessori education, according to her. What she wanted was math and science. She did calculus by 12, while sitting under her desk; she still prefers to sit on the floor. Moving and going to a new school was “hell” for her; in her senior year of high school, she had no friends. Her new school said she was a genius and enrolled her in advanced
self-study. She went to a university on a state vocational rehabilitation scholarship and majored in chemical and electrical engineering. Until diagnosed, she was an engineer at NASA and then worked in another medical device company; she says that those places are “used to aspies, their care, feeding, and capabilities.” Because she is “petite, female, attractive, and funny” she fit in. But she felt “a bit frustrated and clueless on many aspects.” When she took a promotion and moved to her current company, it identified her as an advanced degree candidate and offered to pay for masters and Ph.D. education; she has just started her Ph.D. studies. When she started her master’s program, she applied for disability accommodations at the university which insisted on a diagnosis, was tested and officially diagnosed with Asperger’s syndrome. When she was diagnosed she “felt relieved” and started receiving medical and social help through a psychological doctor and the University.

Daniel. Daniel is a gendervague. They is an “Autistic” whose autism is “professionally documented” rather than being diagnosed as such. Because they believes that “Autism is not a disease, so the concept of "diagnosis" doesn't apply,” they did not answer or answered in an atypical way many of my questions that included the word, ‘diagnosis,’ except the question about whether a respondent was officially diagnosed, to which they answered yes. Among many autistic participants who think “outside the box,” their way of thinking was outstanding. They completed RAADS-14 questionnaire as though ‘other people’ was replaced with ‘autistic other people’ and let me know about it in a section to critique the questionnaire. They was also the only interview participant who preferred to have a video interview though in the end we had an email interview; my emails to set up a video interview “got buried” in their long list and they emailed me their answers right after I informed them that my data collection was completed.
They is a college student and lives in an urban area. They participated in my research for the following reason:

This research was brought to my attention through [an autistic self-advocate’s] mailing list. As an Autistic community organizer, I get a lot of notifications for research, but unlike many of the messages I receive, a study of foodways seemed like something that could have actual benefits for autistic people.

They declined to answer to my questions on what their life was like in brief until they was diagnosed with an autism condition, why an official diagnosis was sought, and how they felt when they was diagnosed, all because of the word, diagnosis. I revised the question to the following, and asked again, apologizing for being not thoughtful enough when I was wording that question for them:

Please briefly describe what your life was like until you recognized that you are autistic and/or you were professionally documented as autistic. If you are professionally documented, why professional documentation was sought for? How did you feel when you recognized that you are autistic and/or professionally documented? When I report your answer, I'll make sure to mention that you raised an issue with the original wording. If you give me permission, I'd like to cite your poem, Points In Space, in my dissertation because that kind of answers some of these questions.

They informed me that they still prefers not to answer because they would prefer people not focus on questions on before/after identification topic. They gave me permission to cite their Points In Space (Obejas37, 2015) poem below, which I find to be a close answer to my questions above.

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37 Daniel Obejas has recently changed their name to Daniel Valencia, according to their ‘Introduction’ section, which has been updated overtime.
For fifteen years I wondered who I was

I tried to ask but my voice could not carry

a silence for which no alternative was offered

In this way they told me my culture was empty

I tried to read but the sensation of a story in my own tongue was always out of reach

I might as well try to feel the sky as if it were braille

In this way they told me I am a sad little star

shining alone in ultraviolet so no one can see me

I refused to believe this, and indeed I discovered the telescope

but upon seeing the galaxy no later did I learn

that the other stars are quadrillions of miles away

I shine with stubborn hope that my light will reach the others

but how do I know they are even watching?

They are just points in space to me

I know nothing more

I have grown to despise the space

emptiness is my jail cell

the other stars in other cells

and the distance between us the bars
In truth I am no star

I am a human being on a rock

but just as the distance shrinks so does my jail cell

I curse the rock beneath me

for it is the space that divides me from my culture

from myself

And then, acceptance

This telescope that showed me the galaxy

this screen that told me about myself

it is not a jail bar

it is the key to the cell

The stars and I may be at different points in space

but we are already one because I am seeing their light

that IS my culture

I do not ring the door bell when I come home

I press the power button.

Alex. Alex is a female who is self-diagnosed with an autism condition. She lives with her boyfriend and other housemates in an apartment in New York City. When asked what motivated her to participate in this research, she answered:
felt motivated to participate in the survey and email interview because, as you know, I am “self diagnosed.” I see this as an opportunity to advance my personal research on Autism and how it may possibly affect me. And also, I am happy to support someone’s research on a very important issue.

After she took an “online test for autism” and her result suggested she is 'Very/Highly likely' to be on the spectrum, she “felt relieved.” Prior to taking the quiz, she was “a bit lost” in her career life because of her difficulty in communication and social relations. She graduated from a [good art college in New York] in 2014, and afterwards, she took on different art jobs. Although she knew the job market was “a bit tumultuous” right now, she felt there was something else holding her back. Through a friend, she was able to obtain a job at a young art gallery in SOHO and stayed there for almost a year. But the parts of the job she found difficult were her interactions with customers, interactions with her bosses, and the general miscommunications she had with them. Although she left on “a perfectly pleasant note,” she felt that she was “holding [her] breath the whole time and never exhaled until [she] quit.” In her search for a new job she went on at least a dozen interviews but still never landed on a proper job. She took on internships in the process just to keep her “spirit up.” Even though she formed very close relationships with her employers she still felt “the sting of improper communication skills.” During her six to eight-month job hunt, she began to reassess what she wanted and what is best. In the midst of this hunt she just happened to take the online test and that redirected her job hunt. She began to research what jobs are better aligned for people on the spectrum. After “great deliberation and research” she feels that she is finally on a more stable and possible career path in Web Development. She believes she may have been misdiagnosed with depression, ADHD, and social anxiety.
Tony. Tony is a male who is self-diagnosed with autism. He worked as a government agent for 30 years and is presently retired. After he retired, he went to a graduate school and received a master’s degree. He is single and lives alone in an urban area. He participated in my research “hoping for more information on the topic and willing to share my experiences to help others.” He was “researching/googling autism issues and saw the opportunity to participate and grabbed it.” He feels he is socially isolated and wants to meet other people like him: “I’d like to know how to meet others like myself. Favorite one liner autism joke: So three Aspies walk into a bar...” When asked about his life until his self-diagnosis, Tony replied, “Always been somewhat hellacious.” He has been picked-on since third grade and it keeps on going. He did not fit in: “I'm different, "a little off" you know, always saying the wrong thing, a know it all, yeah he's smart, but who'd want it at that cost.” He had a dual opinion of himself: “one as social misfit, the other was that I knew I was really smart, IQ 145 in 3rd grade test.” He later considered himself to be “somewhat of a coward” because he could not deal with people especially with respect to starting a relationship, or even just starting a conversation. He eventually “disabused” himself of that idea as he loved scuba diving and riding his Harley. He says, “so it was just around people that my “cowardice” showed up.” His undergraduate days were “filled with people, friends and a few girlfriends. The classes helped, and smoking dope was a way to connect back then.” He did not fit after college again and he did not understand why he did not fit in. But then he read "House Rules" by Jodi Picault about ten years ago and saw himself: “I saw myself unveiled, but to a much lesser degree in almost all categories.” He was “pretty sure of [his] autism as of then.” Subsequently, especially within the last year, he had researched and found out “all kinds of good stuff; much of which explains what/who I am...Researching mostly on line, taking ASPIE
QUIZ, seeing my whole life pattern, it just felt so good.” He was greatly “relieved” when he self-recognized him as autistic:

Now when I think back on things, such as how I’d responded in various social situations that had occurred years or decades earlier (I frequently ruminate, but not so much on the bad things). I no longer think that I’m a screwed up damaged person, I’m autistic! OMG what a relief, I just don’t fit within the dominant paradigm!! If everyone were autistic the world would be much more pleasant; everyone would help the others because of our zero-positive empathy.

His very positive understanding of autism was reflected in his responses to statements about autism in the survey. In a follow-up interview, I asked him if he had heard of the neurodiversity movement. Surprisingly, he was not aware of the movement. When I told him about the online autism community, including autism blogosphere, he replied, “I want to discover such blogs, make contact with those I’ve been thinking of as "The others." I'm rather intuitive and just know things.” Like Alex, he believes his current mental diagnosis is wrong; he says, “The reason I want a Dx is to shake the bipolar (which I am NOT) diagnosis.”

Sally. Sally is a woman with a daughter, Rose, who is non-verbal and with a diagnosis of “autistically impaired” (AI). Sally lives with her daughter in a rural area. Their home is about ten miles out of town and the town population is only about 25,000. Rose graduated from high school and is in a transition program for vocational skills. Sally has a bachelor’s degree and works part-time to take care of her daughter before and after her class. Sally originally completed the online survey as though she was her daughter because my survey instruction was not clear to her. She mentioned that fact when I contacted her for an interview. I filled out another survey for her, changing her original answers as much as I could, asked her to complete the rest of the
survey and excluded her original survey account from the data set. Sally participated in my research about autistic foodways because “the subject matter of food is a very important component in our lives.” She explained how the subject matter of food is very important component in the lives of autistic individuals and her daughter:

For autistic individuals, the intensity of all the senses - smells, tastes, textures, sights, even the sounds (sizzling for example). Food is a total sensory experience! For our individuals, it is something they can all relate to - they don't have to have knowledge or skills to appreciate food and it is something they can all look forward to and communicate about. It is often used as a reward in training exercises and behavior modification as well as social skills and community living training. As for my daughter and myself, food has always been a great way for us to connect and communicate. We love cooking together and she has gained some fantastic cooking skills, which makes her feel competent and achieve some level of independence and choice/control in her life.

Sally says Rose was “basically affected since birth” and attended Pre-primary impaired classes from age three to five. At five years of age she received the official AI diagnosis as she was going into kindergarten and a diagnosis had to be made. The actual diagnosis did not affect Sally: “I knew we would do whatever we could to help her no matter what the diagnosis. She had been affected for so long and it was discussed since age 1, so it was no big revelation.” Sally says that the lack of speech, social skills, and the repetitive and obsessive behaviors were the best indicators of Rose’s autism. Autism has become “a way of life” for her and her daughter over the years: “she has truly blossomed in many ways and it is a joy to watch her mature. Now, I cannot imagine her being any other way!”
In order to verify her answers about her non-verbal daughter’s foodways, I asked Sally how she communicates with her daughter. She said she knows her daughter so well that she “can usually tell what she's thinking” and explained how she communicates with her. Rose uses a lot of gestures, some pictures and some sign language. Sally and staff have tried at times to facilitate the Picture Exchange Communication System (PECS) or an electronic system, but Rose has been mostly resistant to those. Rose does use pictures to make choices (i.e., at restaurants, choosing meals to cook herself and choices about activities). Sally also makes picture recipes for Rose to follow. Sally generates Rose’s choice boards and recipes with Attainment Company's GoTalk software, which consists of numerous photos, illustrations and symbols. As for her making “requests out of the blue,” Rose will get her mother (or staff)’s attention and then gesturing or signing what she wants, hoping they can understand. There are also “standard things” that Rose does that Sally (or staff) can tell what is going on:

For example, when she is constipated, she can't simply tell us, but she "tells" us with her body language - standing a lot, repeated trips to the restroom, complaining of aches and pains anywhere. But generally, she just plain gets cranky and stubborn, which we know means she is uncomfortable.

**Hannah.** Hannah is a female with two sons. Her oldest son, Jason, received a diagnosis of autistic disorder at the age of five. Her youngest has a diagnosis of autism spectrum disorder. She lives with her sons in a suburban area. She has a bachelor’s degree, and Jason graduated from high school. Both of them are currently not working due to disabilities. The reason she participated in this research was to contribute to increasing our knowledge bank on autism because she believes research findings equip her to better help her son:
I enjoy participating in research because I enjoy reading research already performed so that I can help my son with sleep, social skills, and anything else pertinent. I think it's important to continue giving data so that we all can understand Autism a little better. She later said she enjoys sharing experiences about her son because it also helps her feel not so alone.

She first sought out a diagnosis because she thought something was wrong with his hearing; he did not respond when she called him or talked to him. For a while she was convinced that he was deaf, until he had a hearing test and the result indicated that his hearing is fine. His social skills declined right after he turned one year old. When he was diagnosed with “Autism,” she “felt relieved because it explained so much.” His life was very frustrating before his diagnosis because his family did not know how to help him. She was “happy to finally really understand what was going on with [her] son.” But Jason had a lot of difficulty in school; he would not eat and did not make classroom friends. His first doctor said he thought Jason was retarded. Jason did seem to get along with much younger children. He has had a little occupational therapy to help with handwriting and to improve his balance. His behavioral therapy and art therapy have been most useful. Hannah has a great concern about her son’s future because she thinks he will never be able to take care of himself:

My son cannot take care of himself so the family takes care of him. Our worst fear is what will happen to him when we are all dead. He would have to go into a home. As his caregiver, I take him to a psychiatrist and neurologist for his insomnia issues. He does have a physician for chronic constipation and finally is wiping his own bottom (we never thought he would do that on his own). He eats poorly because he has a limited diet (will
only eat certain finger foods). We have made progress with him but I think we have finally come to the conclusion that he will never be ready for an assisted living facility.

Jason has been treated by physicians for his insomnia, anxiety, and constipation.

**In-Person Interview Participants**

There were three in-person interview participants: Mastermind and his mother, and my friend, Drew. When I introduce Mastermind and his mother, I will provide a detailed description on how we met and developed a rapport. As many social situations revolve around food, we ate together whenever we met. Sometimes grocery shopping happened when we spent time together. While his foodways was described in chapters on foodways (along with many other participants’) a more narrative version of some of his foodways is introduced here. In the section on Drew, who is not formally diagnosed, I will focus on describing Drew’s autistic traits, and other characteristics that are more common among autistic people than the general population.

**Mastermind and his mother.** Mastermind is a male college student. He was diagnosed with Asperger’s disorder when he was 15. He was originally diagnosed with PDD-NOS at 4. He lives with his parents in an apartment in New York City.

I met Mastermind and his mother at an autism conference in 2015. Both of them showed interest in my research. Soon after she noticed that her son looked comfortable talking with me, she did not say much, as a way to encourage her son and I talk to each other more. I asked him the meaning of his first name that is foreign. He explained the meaning of his first name, which will be replaced with his chosen pseudonym, Mastermind, in this research, and last name, and his mother’ as well. He talked about how his mother’s name well matches her character. He then said he is very fortunate to have a very loving and supportive mother. He also said he is fortunate to be born in the US because autistic people who are born in his parents’ home country are
considered demon-possessed in many cases, and abandoned or even killed. While talking about the meanings of our names, the rapport between us built to some degree. He then talked about his “impairments” related to autism. I told him that I think his impairments would have been better supported if his environment were more properly designed. Upon hearing that, his eyes shined. My focus on the environment rather than the impairment of a person *per se* seemed to have impressed him. Possibly feeling safe to tell me about his personal matters, he told me how much he was severely bullied throughout his school years: “It was so painful that now I even enjoy pain.” He then said he does not know why he tells me so much about himself while he usually does not talk with strangers. I told him that I think those who bully other people are the ones who lack empathy even though autistic people are considered to lack empathy, and they should feel shameful about their inconsiderate words and behaviors. We then listened to the first keynote speaker of the conference, an autistic author who supports the neurodiversity movement. The speaker first talked about how he was different from his peers, did not fit in, was bullied, and felt extremely lonely. But then he talked about his unique way of thinking and feeling that made him successful. He suggested our society should accept each autistic individual’s difference and uniqueness and support them to thrive. Mastermind was very moved by the speech, and later bought one of the speaker’s books and received a signature from him. After the speech, his mother suggested they give me their contact info so that we can contact each other to have lunch together after we attend different workshops. He wrote both of their full names, email addresses and cell numbers. His handwriting was very neat and beautiful, contradicting my understanding that autistic individuals often have poor handwriting because of their lack of fine motor control skill. I gave my contact info to him. For lunch, we had several options of sandwiches to choose from: ham, turkey and vegetarian sandwiches. He chose a vegetarian sandwich. I asked him if he
is a vegetarian. He said he wants to become a vegetarian someday because Einstein and many other smart people are vegetarians. He was not a vegetarian yet because he likes eating meat. He said he likes halal food from food trucks, particularly chicken over rice with some spicy sauce. His mouth watered while talking about the delicious food. I told him that I like the food very much too, and I live in Jackson Heights where I have easy access to many ethnic foods such as curry, which is another favorite of mine. He was very excited to hear that I live in that neighborhood, because his family trip to the neighborhood to shop for groceries about once a month to buy ethnic food though they live in another borough.

After the conference, his mother and I exchanged many emails, and built a strong relationship. Although I sent emails to both his mother and him, he never replied to my email. But his mother implied that he reads my emails. Soon, his mother and I decided that we all three get together to have a dinner. According to her, Mastermind became really excited about the idea. She asked me when it would be convenient for me to meet up, and I suggested a date and time saying that my schedule is very flexible and I am open for other times. Soon I received an email from “her”: Mastermind replied to my email as though he was his mother. “She” asked in the email, “Do you know how busy he is?” The email detailed his busy schedule, and was extremely formal and somewhat accusing compared to her previous emails or her usual way of talking. I felt “her” email was abruptly cold and distanced. Without knowing that he had written it, I apologized for suggesting that time that is a busy time for him. His mother replied they are all free to meet at the time I suggested. Her emails were full of exclamation marks. We let him choose a place. It was first time for him to choose a place for a social gathering over a meal. He chose Jackson Diner, an Indian restaurant in my neighborhood. When we met in front of the restaurant, we all were so happy to see each other again that it was so natural for all three of us to
hug each other even though neither Mastermind nor I are huggers; he does not like being touched by others like many other autistic individuals and I am from a culture where people do not hug while greeting. His father accompanied us, too. We were escorted to a corner seat near the entrance. Though the corner was near the entrance, it was not too exposed to the passing of customers because the entrance had a vestibule and the entrance door did not face the corner. The restaurant was not too crowded but it was quite noisy. Both his mother and I thought it would become too noisy for him, and she suggested we go to another restaurant that is cozier and more affordable. However, Mastermind wanted to stay there because that place is “nicer”: the restaurant was very neat and decorated with modern ceiling light structures, paintings, and accent lights. We decided to stay following his opinion. A waiter soon came and took our order. While Mastermind was making an order, his father interrupted him several times making suggestions. His parents constantly taught him how to behave in a restaurant because he does not have much experience in such a setting. Mastermind looked a little bothered by that, but did not seem to mind much. While eating the food, his parents helped him pouring sauces because his fine motor skill issues made it difficult for him to hold a sauce bottle and control the amount of sauce he pours. The food was very delicious and we all enjoyed our dinner. His father took many photos of us. Mastermind had a big smile on his face. I did too. He looked very happy to see his parents having big smiles on their faces leaning toward each other while he was taking photos of them.

While we were still eating, his father said he would go grocery shopping. I was surprised to hear that, but they said he often does that because Mastermind does not like going grocery shopping together. Mastermind and his mother would wait somewhere while his father does grocery shopping. We decided to meet where their car is parked, after he finishes shopping. The restaurant soon became too noisy with more people. His mother said she is developing headache.
I felt the same way. Instead of talking there, we decided to continue to talk outside of the restaurant soon after finishing eating. It was so much quieter outside. The weather was nice. We all felt so much better outside. Mastermind said he felt so much better outside though he constantly said he was fine with the noise when we were inside of the restaurant. He said he does not like New York City because it is too crowded and noisy. He asked about my home country, Korea. I showed him some photos that my parents took in the countryside there. He liked the scenery in the photos very much. He said he feels peace while looking at the photos. Though we were standing on a sidewalk in front of the restaurant at night, which might be not considered as the best place to get together, we all three were very happy and enjoyed our time together.

Thinking his father had almost finished shopping, we decided to walk toward the grocery store where his father was shopping. While walking, we passed in front of a small halal meat store. Pointing at the store, Mastermind said he really hates the smell of the store because of the smell of the meat. He said he never enters the store. He would just wait outside the store while his father buys meat there. We arrived at the grocery store where his father was shopping. But he was still shopping inside. We continued our conversation standing on a sidewalk in front of the store. After hearing more about my research on food and food environments, his mother talked about how diet really helped her son’s health. His abdominal pain and constipation have been very much relieved since he began to drink smoothies made of various vegetables and protein powder. More importantly, he does not become hungry too quickly any more. He, too, told me how he had felt better when he started drinking it every morning. Both of them said they want to participate in my research. While saying “use me as a guinea pig for your research. You can open me,” he closed his eyes and opened his arms wide as if he was offering his body to be opened like a guinea pig in a lab experiment. He had a big smile on his face while taking that
pose. He, his mother and I all laughed out loud. I told him, “Oh, thank you, but my research is not experimental. I want to listen to your stories, and will not do any experiment with you as if you are a guinea pig.” While we were talking, his father finally exited the store with so many plastic bags full of groceries. Still, he said he wanted to buy some fish in another store. His father seemed to be really enjoying the shopping. He looked very energetic and had a big smile on his face. It was about 9:30 pm and Mastermind’s mother said it is time to say goodbye. Enjoying our time together very much, he said it is not too late and wished to spend more time together. He looked at his mother with yearning eyes a smile and gently patted her face and hair. His father asked us to wait for him near his car and quickly walked away to buy some fish. We three continued our conversation walking toward the car. When I told him that I have a friend who seems to be on the spectrum, he asked me if my friend sniffs to smell food before eating. I told him that the friend sometimes does. He smiled.

After that night, his mother and I continued to exchange emails. I was invited to their house five times and I had the privilege to learn more deeply about what it is like to live as an autistic person, their understanding of autism and Mastermind’s autistic foodways.

**Drew.** After hearing about Asperger’s syndrome from me and reading about it, my friend, Drew, now considers *themselves* to be on the autism spectrum in the area where a curve of those with an autism diagnosis and a curve of those without the diagnosis overlap in Baron-Cohen’s Autism Spectrum Quotient (AQ) continuum. *They* currently lives as a housemate of a coworker in employee housing in a suburb.

Drew and I became close friends partly because I once misunderstood what *they* meant by “almost.” *They* said, “I almost cried” after hearing that I was scammed by my alleged future “housemate” I had found online and I lost several thousands of dollars. *Their* voice over the
phone sounded low like the one of someone who is very sad. Hearing that my checking account balance became even negative because of the incident, *they* also offered that *they* could lend me a few thousands of dollars. I was deeply moved by *their* kindness, which I did not expect at all from *them*. I felt *they* was similar to a main character in a famous novel, who was later found to be the kindest person although the person was originally misunderstood as ill-mannered. I had had prejudice against *them* thinking that *they* lacks empathy because I had been previously annoyed several times by *their* inconsiderate comments on me and others. For example, to one of our female common friends, *they* once said, “You are so out of shape” while snowboarding together with her and other friends. After Drew and I became close friends, I was surprised to hear what *they* meant by *they* “almost cried.” When I told *them* how much I was moved by *their* kindness and the “fact” that *they* even cried, *they* laughed and said, “No, I didn’t cry.” I asked if at least *their* eyes was slightly wet. *They* replied, “No, my eyes didn’t even get wet. Having the eyes getting wet is part of crying. “Almost” means “NOT”. When you say “I’m almost there” you are *not* there. So, “I almost cried” means “I didn’t cry and my eyes were not even wet. And, the reason why I almost cried was because I thought “How come she is so stupid and naïve and deceived like that!” Though I was a little disappointed and embarrassed to hear that, I did not mind. I was already in the mode of trying to overcome my prejudice.

However, the more we became close to each other, the more frequently I became perplexed by Drew. One day, we were in Chinatown in Flushing, NY to buy something for me before meeting some of my friends to whom I wanted to introduce Drew. As usual, the area was very crowded and noisy with lots of buses, cars, train, and people; many shop signs with strong colors were visually overstimulating. We entered a Korean store to buy something for me. The store was too brightly lit with countless numbers of fluorescent lights that almost covered the
entire ceiling. *They* looked “somehow” becoming gradually irritated and asked me to buy quickly. While I was still picking and choosing, *they* suddenly yelled at me and left the store without telling where *they* was heading to. I immediately ran after *them*, but *they* shouted, “LEAVE ME ALONE!” I felt I had better stop chasing after *them. They* soon disappeared into the crowd. A similar incident happened when we were in Koreatown in Manhattan, which is also quite crowded with people and shop signs. *They* complained about the “stinky” smell and stuffy air coming from the area, which has many Korean restaurants. I took *their* complaint about that area personally because I thought *they* should show some respect for part of my Korean culture, and did not care about *their* suffering. A “negative atmosphere,” to use Drew’s word, developed between us, and *they* became very hostile to me and suddenly left the place again in the same manner as before. I would have ended our friendship if I had not soon read a news article that explains Asperger’s syndrome.

The article provided me with some clues about Drew’s way of thinking and sensitivity to environmental stimuli. I then read Tony Attwood’s (2007) *The Complete Guide To Asperger’s Syndrome* and many academic articles on the topic. I was convinced that Drew has many traits of the syndrome and felt deeply sorry for misunderstanding *them*. I shared with Drew what I learned from the book and other academic articles. *They* first did not like the idea of being “labeled.” But as I shared more detailed descriptions about Asperger’s syndrome, *they* became more interested in it. Unlike many adults who were (self-) diagnosed with Asperger’s, *they* did not have a moment of “feeling relieved” after learning about the syndrome. *They* said *they* “did not try to fit in” when *they* was a child or a teenager, and the university *they* went to and *their* workplaces had been “full of people like [*them*].” Whereas *they* often looked uneasy when *they* met some of my friends, who are mostly non-autistic, *they* looked happy and relaxed when *they*
met *their* colleagues who went to school together studying the same major. *They* joked using some concepts or words from the major and everybody laughed together. I was the only one who did not understand *their* joke and felt uneasy. However, the notion of Asperger’s syndrome still helped Drew understand *themself* and others, including me. For example, *they* now understands why *they* felt urged to read many books on facial expressions, emotional intelligence, executive functioning, and many other areas that people on the autism spectrum have difficulties with.

Using some of the subtitles of Attwood’s *The Complete Guide To Asperger’s Syndrome* as a framework, I will describe *their* autistic traits, most of which are related to *their* foodways.

*Language.* As shown in the introduction on *them*, Drew’s usage of language is very literal. *They* seldom says “I am sorry” or “Thank you.” The reason is because *they* thinks words cannot change any situation. *They* says, “I get madder when I hear that. So don’t say that to me. It doesn’t work.” *They* also considers those who thank “for nothing” or too often are “fake.” Drew feels not awkward when *they* and another person sit nearby in a small space without having any small talk even in a social event. *They* would not initiate small talk unless the other sends *them* any cue to do so. *They* would never call *their* friends just to say hi and see how they are doing.

*Their* speech used to have some peculiarities in terms of tone, pronunciation, rhyme, and word choices. When Drew was young, *they* spoke monotonously like priests, who would speak monotonously without emotions during the mass, and some of *their* colleagues told *them* that *they* spoke like a robot. *They* does not speak that way anymore though *they* does not speak with strong intonation either like some people, whom *they* finds usually to be “fake.” Some people also used to point out that *their* pronunciation was not correct. *They* now wants to receive speech therapy to become more “charismatic.” *They* says *they* does not have charisma and people do not
easily believe what they says: “Even when I tell my birthday, people think I am not sure of it.”

They also used to unconsciously speak with rhymes to the point they felt annoyed by their own rhymes, and make constant efforts not to speak with rhymes. Their use of language was pedantic as a child. They heard from some of their colleagues from high school that they spoke using premade sentences. They says that other people also use many premade expressions such as “how is it going?” as they uses premade expressions such as “to be or not to be”; they asks “What is the difference?!”

Sensory sensitivities. Drew is sensitive to many kinds of smells. They is distracted even by smell from fresh banana peel in a room. They abhors perfume smell. Passing by a duty free store in an airport is avoided because of the perfume smell from the store. They also once asked their workplace to prohibit employees from wearing much perfume because they developed headache from one of their officemates’ strong perfume. When an officemate in another workplace had “stench” body odor, they had headache again and asked for another office. The workplace did not have an available office and provided them with just an air purifier, which was “better than nothing.” To avoid smell from food waste at home, they keeps tightly sealed food waste in a fridge freezer until putting it outside. They is also sensitive to sound. They used to be awake around 4 or 5 am because they heard cars passing by even though they lived in a residential area in a suburb area without heavy traffic, and because they heard their dog licking his paws while grooming himself in the early morning. When they shared an office with others, they wore a noise cancellation headset. It helped them focus better by blocking noise as well as preventing their officemate from talking to them.

Motor skills. For having poor body coordination skills, Drew was always the last one to be picked to join a game with balls: “So, I was always the judge…” Their coordination was poor
especially in the morning. They used to bump into furniture, flip cups, and drop things when they was “forced” to get up early because their school started early. Their handwriting is almost illegible to me.

Alexithymia. Alexithymia is inability to identify and describe emotions in the self. It is very common among autistic adults. A study found that 85% of the adults with autism spectrum disorder has alexithymia (Hill, Berthoz, & Frith, 2004). Drew is not easily aware of their own emotion and does not effectively communicate about how they feels. They does not like vague questions about their feeling, such as ‘How are you?’; they does not know how they feels and how much detail the other wants to hear. While they has a strong vocabulary in general, they has a poor vocabulary regarding emotions; they says, “There are four emotions: angry, sad, fear and happy. Is there anything else?” Even when they becomes angry, they would not show any clear sign that they is becoming angry, and would suddenly burst out. I had to develop my own antenna to detect their subtle signs of being disturbed. Identifying other people’s emotions also was very difficult for them. They says they is now much better in telling others’ emotions after reading many books on emotions and facial expressions written by Paul Ekman: “Now I can easily detect those who lie or cheat.” Feeling hungry is not exactly an emotion, but that is another feeling that is difficult for them to identify. They usually does not feel when they is becoming hungry, skips meals and then suddenly feels too hungry to think clearly about how to access food. Their definition of being hungry is very literal: “You don’t know what hunger is. It is not just a stomach growling. When you’re hungry, you shake, you can’t think properly.”

Stimming. Drew does not engage in any self-stimulatory activity except very occasionally shaking their legs or drumming their fingers while eating a very delicious food out of happiness. They said they never told anything to their mother when the food she prepared was very
delicious. They would just shake their legs while eating the delicious food, and their mother would know they is enjoying the food; when the food or the smell of the food is bad, they would say “It is horrible!” and would not touch the food anymore.

Sanitation. Drew is strict regarding cleaning anything they would directly touch with their hands whereas they does not clean others things, such as dishes and floors, as frequently as expected. It may appear that they applies a double standard in dealing with maintaining sanitation of their items and surroundings. Their apparently double standard behavior is actually based on a simple principle of minimizing germ exposure. They would clean borrowed library books with alcohol when borrowing them is unavoidable; they would also frequently clean their keyboard and smartphone with alcohol; they does not like touching cash and would wash hands after touching bills; partly because of concerns on germs they would not use public transportation except when it is absolutely unavoidable.
Appendix H

Responses to the Rest of the Statements about Autism

*Autism is a part of an individual’s identity.*

![Bar Chart: Autism is a part of an individual's identity](image)

**Figure H1. Autism is a part of an individual’s identity**

Most diagnosed participants agreed with the statement ‘Autism is a part of an individual’s identity.’ Particularly, more than two thirds of them (14) ‘Strongly agreed’ with the statement. The pattern of these responses is almost directly opposite to that of the responses to the statement ‘Autism needs to be cured.’ It is possibly because most diagnosed participants, who are the majority of the participants, consider someone’s identity should not and cannot be cured. The responses to the statement ‘Autism is a part of an individual’s identity’ are also in line with the answer “Because I am,” which was provided by several diagnosed participants as an answer to the open-ended question on why they think they are on the autism spectrum. I will introduce Daniel’s definition of autism later, which emphasizes their understanding that ‘Autism is a part of an individual’s identity.’ The number of self-diagnosed participants who chose ‘Strongly agree’ also was the highest. While the participants’ response pattern to this statement
was similar to their response pattern to the statement ‘Autism is a way of being,’ there were a few participants who disagreed with this statement.

*Autism needs to be celebrated.*

Figure H2. Autism needs to be celebrated

The number of participants who ‘Strongly agree’ with the statement ‘Autism needs to be celebrated’ was higher than the number of participants who responded to any other choices; only six of the thirty-two respondents indicated any disagreement. Diagnosed participants more tended to agree with the statement, but a number of diagnosed participants’ responses were ‘Disagree’ or ‘Neither agree nor disagree.’ There were only two participants who ‘Strongly disagreed’ with the statement and all of them were self-diagnosed participants.
**Autism is a gift.**

The number of the diagnosed participants who ‘Neither Agreed nor Disagreed’ with the statement ‘Autism is a gift’ was significantly higher than that of those who chose other options, and two diagnosed participants chose ‘I don’t know.’ It is possibly because many diagnosed participants were aware of both strengths and weaknesses of autism (e.g., executive functioning), considering their answers to the question about the reasons they consider themselves on the autism spectrum and the question about their own definition of autism. Also, some of an autistic person’s strengths and some weaknesses may be considered the opposite way depending on the persons’ environment and situation. For example, Lydia’s tendency to focus on details may be interpreted differently. All self-diagnosed participants chose different options, showing they do not have a shared opinion about whether ‘Autism is a gift.’
Figure H4. Autism is a natural human variation

Most of diagnosed participants (18) answered that they think autism is ‘Completely’ a ‘natural human variation.’ Some of the diagnosed participants who answered that ‘Autism is a disorder’ and ‘Autism needs to be treated’ also answered that autism is ‘Completely’ a ‘natural human variation.’ It is likely that they think having a disorder that needs to be treated is a ‘natural human variation.’ A small number of diagnosed participants chose from ‘Not at all’ (1), to ‘A little’ (2) to ‘Somewhat’ (2). Self-diagnosed participants showed various responses to the statement ‘Autism is a natural human variation.’
**Autism is a genetic condition.**

![Autism is a genetic condition](image)

**Figure H5. Autism is a genetic condition**

Generally, participants considered that ‘Autism is a genetic condition.’ Almost half of diagnosed participants (11) answered that autism is ‘Completely’ a genetic condition and five answered that autism is ‘Mostly’ a genetic condition. However, a tiny number of participants answered that autism is ‘A Little’ or ‘Not At All’ a genetic condition. Three out of four of them were diagnosed with an autism condition when they were children. A relatively high number of participants chose the ‘I don’t know’ option while a smaller number of participants chose that option for a similar statement ‘Autism is hardwired,’ which is also about a genetic aspect of autism.
*Environmental pollution causes autism.*

Most diagnosed participants (17) answered that environmental pollution is ‘Not At All’ a cause of autism. Their answers imply that they do not consider a possibility of any external substances interacting with their genetic makeups to result in autism. Even some of those who answered that autism is ‘Mostly,’ ‘Somewhat’ or ‘A little’ a genetic condition answered that environmental pollution ‘Not At All’ a cause of autism. While only two out of 23 diagnosed participants answered that they ‘Don’t know,’ two out of six self-diagnosed participants answered they ‘Don’t know.’ No participants answered that autism is ‘Mostly’ or ‘Completely’ caused by environmental pollution. Diagnosed participants clearly showed a different pattern in responding to this statement compared to self-diagnosed participants.
**Autism is a brain condition.**

![Autism is a brain condition graph]

Three-quarters of the participants considered that autism is ‘Completely’ (15) or ‘Mostly’ (9) ‘A brain condition.’ Their responses reflect the mainstream biomedical focus on the brain as the locus of autism. Compared to self-diagnosed participants, diagnosed participants were largely divided to a group who answered that autism is ‘Completely A brain condition’ (11) and a group who answered that ‘Autism Is Mostly A brain condition’ (8).

**Autism is a whole body condition.**

![Autism is a whole body condition graph]

Figure H8. Autism is a whole body condition
The number of participants who answered that autism is completely a whole body condition was larger than that of those who answered differently regarding the degree to which autism is a whole body condition. Nine out of 23 diagnosed participants answered that Autism is completely a whole body condition and 6 answered autism is mostly a whole body condition.

*Autism is hardwired.*

![Autism is hardwired](image)

Figure H9. Autism is hardwired

Most participants answered that autism is completely (18) or mostly (7) hardwired. A diagnosed participant was the only one who answered that autism is not at all hardwired.
**Autism is a biomedical condition.**

Generally, participants did not have a clear idea about whether ‘Autism is a biomedical condition.’ Among the 15 statements, the statement ‘Autism is a biomedical condition’ received highest number of ‘I don’t know’ response. Thirteen out of 32 participants chose ‘I don’t know’ when they were asked what they think about the statement ‘Autism is a biomedical condition.’ Except for the option, ‘I don’t know’, the largest number of diagnosed participants chose the ‘Not At All’ option. In contrary to diagnosed participants, no self-diagnosed participants answered that autism is ‘Not At All’ or ‘A Little’ a biomedical condition.

Figure H10. Autism is a biomedical condition

![Autism is a biomedical condition chart](chart.png)
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