Making up and caring for ‘autism’s child’ in Ethiopia

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Thesis submitted to the
Faculty of Graduate and Postdoctoral Studies
In fulfilment of the requirements
For the Master’s of Arts in Anthropology

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Faculty of Social Science
University of Ottawa
May 2019

Abstract

One fundamental conceptualization of the biomedical category of autism is that of the withdrawn child, isolated in an impenetrable world. This trope, and associated neurobiological, cognitive and linguistic markers, have become central to how autism is recognized in both academic research and in popular understanding. In this paper, I draw on fieldwork in Ethiopia, where the first education and care center for autism was founded in the capital of Addis Ababa in 2002. My research explores the relatively recent introduction of the diagnostic category, working principally with Ethiopian parents who have identified and sought care at the center, and educators on staff. I find that the adults understand these children not as withdrawn, but in terms of three key characteristics: a "tied mouth," an inability to listen, and experiencing inner disturbance. Colloquially, any of these three may mean that a son or daughter is "*ye otizm lij*" [lit. autism's child]. Drawing on ethnographic material, I show how, for these parents, these three markers shape how they understand and work to care for their children, and therefore, autism.

Acknowledgments

Writing this document would not have been possible without the support and encouragement of some very dear people.

Foremost, I would like to thank my supervisor, Meg Stalcup, for the time, energy, and wisdom she has provided me. Without her constant push and creative strategies to keep me moving forward in the face of writing blocks and other setbacks, I am certain this thesis would have never been completed. And thanks to my committee members, Loes Knaapen, Ari Gandsman, and Kelly Bronson, for being available for feedback and providing lines of thought to take my work further. I feel privileged to have been amidst such dynamic thinkers.

My sincerest thanks go to all of those at the Joy Centre in Addis Ababa. To all the teachers and supporting staff, thank you for showing me the ropes and including me in your community. To the parents especially, thank you for taking the time to share your experiences, from the most joyous to the most heartbreaking, with someone you had basically just met.

Thank you to all my relatives in Ethiopia for making my three-month stay so comfortable and for teaching me that getting lost is how you learn to find your way.

Thank you also to a dear few who bore the burden of listening to my ramblings about writing this thesis for the past two years and not once rolled their eyes when I told them (for perhaps the thousandth time), “I’m in the last stage of writing”.

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Introduction.

Who is "*ye otizm lij*" (lit. autism's child)?

One afternoon after the school day at the Joy Centre for Children with Autism had ended, Genet, the mother of one of the older children enrolled there, struck up a conversation and began telling me her personal story of raising her child.[1] When, at two years of age, her daughter had not yet begun talking, Genet took her to the Black Lion Hospital located, like the Centre, in Addis Ababa, Ethiopia. Her daughter was assessed, by who she described as a brain specialist, and informed that her daughter had autism. The doctor explained that due to the nature of this condition, although the child could show some improvement, she would be this way for the rest of her life. Genet struggled to care for her daughter in this condition as best she could but it was not until the girl was enrolled at the Joy Centre that she saw the beginnings of improvement, even beyond that to which the doctor had referred. Her daughter began talking, learned how to use the washroom independently and lessened how much she would rock back and forth or flap her arms. Genet tells me of a moment in those earlier days that she will never forget. Another parent, seeing her daughter's improvement, had said to her, "*Yanchi lij iko, ye otizm adelechim*" [literal translation. "You know, your child is not autism's."]. Genet looked to me and said, "They must have seen something good in my daughter. This really encouraged me. She might have some behaviours that make her different from normal kids, but she is not autism's."

There is no specific Amharic word that encompasses the set of behaviours existing under the category of autism. Instead, the English word "autism" has been adopted into the language.

[1] All names have been changed.

While speaking about children with this condition, parents would refer to them in one of two ways. They could be '*ye otizm lij*', literally translating to 'autism's child'. Alternatively, some parents would describe these children in terms of specific behaviours (such as the child's inability to speak, flapping his or her arms, or rocking back and forth). This in itself is notable, since in the Euro-American context autism is a biomedical term used to describe a configuration of symptoms which are categorized in terms of cognition, social competence and behaviour. While this biomedical framing of the condition is newly present in Ethiopia, parents, such as Genet, spoke of autism exclusively in terms of the specific unusual behaviours (rocking back and forth or making repetitive sounds for example) he or she engaged in, behaviours that are associated with autism and therefore shaped the child as *ye otizm lij* (lit. autism's child).

Research Aims and Conceptual Framework

> The most impressive thing is his detachment and his inaccessibility. He walks as if he is in a shadow, lives in a world of his own where he can't be reached…[h]e seems almost to draw into his shell and live within himself.
>
> Leo Kanner, 1943.[2]

Leo Kanner, a psychiatrist in the United States, wrote this description of a child in his care in 1943. He identified eleven cases where children exhibited such symptoms and grouped these cases for the first time under the label of "autism" (Solomon 2010). Although this description may, in reality, be too specific to describe every autistic child, something along these

[2] Kanner, Leo, pp. 218 and 236; cited in *Sense and the Senses: Anthropology and The Study of Autism,* Solomon 2010, 247.

lines fits the common idea of the autistic child in popular imagination (Wallis 2006; Huppke 2007; Kaufman 2007). This image of the detached child, lacking full understanding of the social world around them, trapped in isolation, is one that has proliferated since the publication of Leo Kanner's notes. Autism as a trope for withdrawal into an isolated and impenetrable world has been a fundamental part of the conceptualization of this condition. The varying individual biomedical markers of autism, such as differences in neurobiological characteristics and the lack of certain cognitive and linguistic abilities, have been encompassed into a larger idea of what it means to be autistic and it is by this idea that autism is often recognized.

The spread of this idea of autism is in part because, globally, prevalence rates of autism have increased from one in 2,500 children in 1978 to around one in 100 today (Hollin 2014, 1). Autism has even been called the pathology of the present decade (Hollin 2014, 1), inciting debates over whether its increasing prevalence can be classified as an epidemic. Scientific and popular debate has focused on whether this epidemic stems from expanded diagnostic criteria for autism, heightened awareness and thus accurate diagnosis where before autism went undetected, or an actual increase in cases (Grinker 2007; Kaufman 2010). At the same time, autistic people, advocates, and some academics have begun shifting the discussion to the value of autism as a form of neurodiversity (Silberman 2015).

Much of the discussion around autism has occurred in the context of Western countries (the UK, Europe, and North America). This research, along with biomedical principles, classifications, and interventions developed in this context are quickly travelling around the world in the name of biomedical and technological development, including to Ethiopia, where I have situated my project. Ethiopia is thus a privileged site for examining the introduction of the

epistemological and clinical practices that bring "autism" into being. Further, as a site for this research, Ethiopia is at least equally significant on its own terms for, I argue, there were existing ways of knowing and caring for what is now understood to be autism which are important in their own right, as well as for the transformation they are undergoing.

In 2002, the very first care and educational centre that offered services for children with autism was established in Ethiopia, founded by Zemi Yenus, an Ethiopian mother whose child has autism. The Joy Centre for Children with Autism began with a handful of children and by 2016, the Addis Ababa-based centre was providing therapy and education to over seventy students, with plans to expand to five hundred. The founding of the centre, and its striking growth, represent more than just a new site for little-available psychotherapy and education services. More fundamentally, I argue, the "autistic child" became a category of person for parents in Ethiopia, one that they recognized and for which they could seek treatment.[3]

While this new way of knowing autism in Ethiopia is notable for the way it has appeared and been institutionalized, at the same time I suggest that there is (and has been) existing, emic knowledge which is overlooked and masked by the very process of introducing new knowledge. This emic knowledge—ways that were already prevalent for naming, understanding, and dealing with something related to what we call (speaking through the norms of North American and European mainstream medicine) autism—has been shared among Ethiopians rather than collected in formal research. This kind of knowledge can be hard to access or trace, and even risks being erased from the narrative of autism's introduction in Ethiopia. In my work, however,

[3] To clarify, when I refer to the category of the "autistic child" coming into being, I refer the ongoing process of existing knowledge (surrounding the behaviours that are now being enveloped in a single category) that has been shared and shaped and is continuing to do so with the introduction of autism as a biomedical concept.

I found that these existing ways of understanding the behaviours now recognized as autism are still present, reframed and compiled to fit into a biomedical category.

In its early stages, my research was lead by the general question, "How is autism understood in Ethiopia?" Being that in Western contexts the conceptualization of autism is reliant on understandings of normative experiences, I hoped to explore the interaction between the transplantation of this term and the way Ethiopians think about normal experience. However, over the course of my fieldwork, it became apparent to me that the locus of this interaction is within the parent's experience of caring for a child with autism. Parents are almost always the primary caregivers, and hence decision makers as to how they will care for their child. When a parent finds that their child has particular needs, the responsibility falls to them to understand and care for those needs. In this context, my work aims to explore, "How do Ethiopian parents understand and care for their children who have autism?"

In response to this question, my thesis is organized into three chapters based on three key markers of autism that I propose as a conceptual framework to explain parents' understanding of autism and their children. The first chapter addresses the parents' experience of their child's verbal regression. All of the parents I spoke to referred to their child's *aff meftat* [lit. untying the mouth], an Amharic idiom used to explain when a child first begins speaking. I discuss how parents place autism at the crux of the interference at this developmental step. Whether the child never reaches the point of 'untying their mouth' or regresses in the sense of 're-tying their mouth', parents saw this as the primary sign of abnormality (and therefore autism) in their children. The second chapter explores listening as an element of the parent-child relationship. In referring to their child's inability to *mesmat* [lit. to listen], parents spoke of their expectations of

obedience and the way that autism shapes them. The third chapter illustrates the parents' understanding of their child's emotional capacity when they say *terebishwal* or *terebishalech* [lit. he is disturbed or she is disturbed]. The way that Ethiopian parents understand their child with autism as being capable of experiencing a deep inner turmoil is contrary to the traditional image of the withdrawn and emotionally stunted autistic child in the West. For the parents, each of these markers was initially just a sign of some difference in their child. Put together, beyond some difference, the child is understood as having undergone some fundamental change.

This fundamental change is summed up in the phrase "autism's child". In one sense, it is simply a colloquial way to describe children who have autism in Amharic. In another sense, this phrase reflects how the parent understands their child and the condition. I believe the use of the possessive is significant for the way it illustrates the Ethiopian parent's understanding, particularly considering the historical context of spiritual interpretations of medical (especially psychological and developmental) conditions in Ethiopia. The idea of autism as some entity that possesses the child could be drawn from the historical interpretation that a child who never begins speaking or one who regresses to the point of not speaking, for example, is spiritually possessed (Tekola et al. 2016; Tilahun et al. 2016). Instead, in my work, I found that the possessive implies a kind of belonging, similar to the way a child belongs to a parent. This sense of the possessive is not necessarily negative. Describing the child as belonging to autism is reflective of the key argument I will suggest: the parent's framing of their child as belonging to autism is evidence of that parent's struggle to care for their child. As "autism's child", the parent envisions their son or daughter as inaccessible in particular ways (namely in the form of a 'tied mouth', an inability to listen, and experiencing inner disturbance) . It is by addressing these

particularities that parents are trying to reclaim their child through a constant and ongoing effort to reframe and transform the ways they care for their child.

Summary of key markers forming Ethiopian parents' conceptualization of 'autism's child'

Aff meftat [lit. untying the mouth]	This idiom is used in reference to whether the child never reaches the point of 'untying their mouth' or regresses in the sense of 're-tying their mouth'; parents saw this as the primary sign of abnormality in their children.
Inability to *mesmat* [lit. to listen]	Parents spoke of their child's inability to listen and the way this inability interfered with their expectations of obedience.
Terebishwal* or *terebishalech [lit. he is disturbed or she is disturbed]	Parents understand their child with autism as being capable of experiencing deep emotional turmoil, which is contrary to the traditional image of the withdrawn and emotionally stunted autistic child in the West.

Methodology

In May 2017, I went to live in Addis Ababa, Ethiopia for three months. I volunteered at the Joy Centre as a teacher's assistant. The Joy Centre is a school that offers to teach and care for children with autism. As these kinds of services are extremely limited in Ethiopia, at approximately 70 enrolled students, the school is at its maximum capacity, with hundreds of children on the waiting list. Enrolment is prioritized and granted based on need, both on the part of the parent and the child. A formal diagnosis of autism is not necessarily a qualifier for enrolment. Specific staff at the Joy Centre assess the child's case based on an autism assessment tool and an observational session with the child. Children demonstrating severe disability (what may also be described as falling on the severe end of the spectrum) are viewed as higher priority. Further, parents who demonstrate an extreme financial need are also prioritized based on the

centre's ability to partially or fully cover the child's enrolment fees. My role involved working with students on varying educational and therapy tasks based on their individually-designed programs. During this time, as I worked with the teachers and children, I became embedded in the daily routines of this community.

My research was predominantly conducted in Amharic, one of the official and most commonly spoken languages in Ethiopia. While most Ethiopians have a fair comprehension of English, encounters most naturally occur in Amharic. As a fluent Amharic speaker, I did not use a translator. With parents, it was important that I foster a sense of comfort, as they often shared their vulnerabilities with me through the telling of their stories. Beyond developing rapport, the process of translation presents its own issues. I anticipated that there might be significant phrases or terms that could not be easily translated into English. While it would be possible to simply explain those terms in English with relative accuracy, I believe that a loss occurs in the process of that translation. Particularly in the case of my work, which partly focuses on existing knowledge of autism in Ethiopia, this existing knowledge is inevitably embedded with the history, norms and values of the people in this place. This is all communicated through their language. As I spoke with my interlocutors over the course of my fieldwork, I noticed the recurrent use of certain key phrases, which is indicative of some shared knowledge. I decided to keep these phrases in their original form to emphasize the ways this shared existing knowledge has shaped parents' understanding of autism.

A week into my time in Addis Ababa, I was walking up the street to the Joy Centre one morning when a woman walking towards me stopped me. Pointing to the centre, she said, "You're one of the new teachers, aren't you?" I replied that I was a teacher's assistant and that I

would only be there for the summer. Then she said to me, "You know, your accent is a little different. Are you from the Tigray region?" As an Ethiopian, born and raised in Canada, I was surprised and quite flattered that my spoken Amharic had not given me away as 'a diaspora', as I was often called there. When I explained my background to her, she was in disbelief, "But you seem just like us!" "Well, even though I was born and live in Canada, my parents lived here most of their lives. So when I'm at home, we only speak in Amharic and we eat *injera*[4] all the time!" I said, kind of jokingly. Laughing in response, she quips, "So your parents raised you as a real Ethiopian, didn't they?"

Slight as it may seem, my ability to speak Amharic fluently went quite a ways in eliminating some amount of perceived difference between myself and the parents. Shared language acted as a tool for building familiarity and rapport with parents as it implied a figurative shared language, a mutual understanding. Alem, as I later learned was the woman's name, and I grew fairly close over the course of my stay since she had a son enrolled at the Joy Centre. At a later point, we had another conversation where she explained to me that she was impressed at how well I was doing my work considering I wasn't born there. The extent of my sensitivity towards the plight of the different parents and children in the community and my understanding of their values such as obedience and faith were particularly surprising to her. I explained that while I haven't lived in Ethiopia, my parents instilled in me at a young age the importance of knowing where I come from. "That's why. That's why I didn't realize you were from Canada. The way you talk, the way you approach the teachers and the students, you're like us." My purpose here was not to erase the differences between Canada and Ethiopia but, while

[4] Traditional Ethiopian food.

acknowledging those differences, to foster a familiarity between myself and the parents that would allow for open and honest dialogue.

As awareness of and services for the care of autism are still fairly minimal in Ethiopia, parents are the primary and oftentimes sole caregivers to children diagnosed with or presenting as having autism and the responsibility of negotiating the health and educations systems in order to find the appropriate care for their child falls to them. Due to a history in Ethiopia where children who exhibited behaviours such as rocking back and forth, and unresponsiveness to social cues were often viewed as bewitched, or possessed because of their parents' sins (Tekola et al. 2016; Tilahun et al. 2016), most parents have navigated the journey towards understanding and caring for their child's condition in isolation, some even in secret. In Ethiopia's rapidly changing health system, the establishment of newly available sites of care are leading in the pushback against parental and child stigmatization. However, many parents confessed to me that even today it is only within a community like the Joy Centre that they feel truly supported, encouraged and understood. It was important for me to present myself as supportive, encouraging and understanding in order for these parents to feel comfortable being open and honest with me about their difficult journeys. My Ethiopian heritage facilitated the parents seeing me as such.

This project is framed around those parents who were able to both identify their children's specific behaviours as signs of difference and found ways to care for them, namely by enrolling their children at the Joy Centre. I volunteered at the centre as a teacher's assistant in order to become a member of that community and develop relationships with these parents. Since the Joy Centre functions as a school, my role involved going to the centre from Monday to

Friday for the entire school day (9am to 3pm). The day was broken up into periods during which each class (organized by age group and behavioural skill level rather than academic level) would rotate through different activities (e.g. exercise class, occupational therapy, music class, academics, neighborhood walk, community excursions). I worked with the teachers in each class and I was assigned to work individually with different students. This allowed for natural encounters with the parents of these students during the morning drop-off and afternoon pick-up periods. These brief and daily meetings were the gate towards developing relationships with parents, as discussing their child's day was a comfortable common ground. For most of these parents, my approach to understanding and caring for their child through my role was a sign that they could be open and honest with me about their experiences. The longer I worked at the Joy Centre, select parents would seek me out, even after I was no longer working with their child.

In addition to this immersion in the field, I conducted eleven audio-recorded semi-structured interviews. Two of these interviews were with two of the head teachers at the Joy Centre. These two women were present in the early days of the Joy Centre's founding and worked closely with the founder, Zemi Yenus, herself as well as with the parents in this community. As such, they have been witness to the parental experience of autism in Ethiopia since and over the course of the introduction of autism as a biomedical category.

The other nine recorded interviews were conducted with parents. While I interviewed six mothers and two fathers, I use the term 'parent' to include my interview with a young woman who is the sister of one of the children at the Joy Centre. She explained to me that since their father is not a part of their lives and her sister's condition has been difficult to cope with, the responsibility of caring for her sister has fallen on her shoulders. And while this young woman

may not be a biological mother, she embodies the mother figure in every other sense. Of the parents I interviewed, they all fell in varying places on the spectrum of age (from young adult to early sixties), socioeconomic status (although predominantly low and middle income with select higher income parents) and religious affiliation (Orthodox Christian, Pentecostal Christian, Muslim and Jehovah's Witness). Marital status did not seem to be a significant factor in these individuals' roles as parents. Whether single, married, divorced, widowed, or what would be considered common law, each of these parents communicated that the care of their child was solely their responsibility and therefore their journey in understanding autism and caring for their child was individual.

I must note here that while it would have been enriching to conduct a recorded interview with Zemi Yenus, mother and founder of the Joy Centre, this was not possible due to her busy schedule. However, during the opportunities we did have to chat, Zemi was very open and honest about her experience of autism in Ethiopia. Being a pioneer and an idealized figure in this area of experience, Zemi's story was brought up in many of my conversations with parents. She is revered as a kind of hero for her bravery and perseverance in fighting for and establishing a place where her son, who diagnosed with autism abroad at a young age, and other children like him can be educated and cared for in her home country. Further, with her son's progress from being non-verbal to speaking for the first time at age sixteen, Zemi's experience has been crafted into the ideal narrative of success that shapes many of the parents' understandings of their children.

A Medical Anthropology of Autism and the Ethiopian Context

In exploring the way that a biomedical category such as autism is understood within the

specific context of Ethiopia, I draw on medical anthropology and related science and technology studies literature to provide a range of tools to first explore autism as a category and then I delve into the significance of Ethiopia as the backdrop for my work, with a specific focus on religiosity and mothering. My findings are rooted in the three markers of autism that I observed to be significant over the course of my fieldwork. I rely on the literatures mentioned above as tools to analyze these markers. Additionally, I draw on health activism literature to identify the parents that bring their children to the Joy Centre as activists of a kind, by virtue of that decision as well as the care-work they are engaged in.

'Making up' autism's child

The specific social and cognitive symptoms compiled into the condition autism often form a specific characterization of those to whom the label is applied (e.g. inability to understand social cues, inflexibility with routines). Autism used to refer to excessive hallucinations and fantasy in young children (Evans 2013, 4). Bonnie Evans argues that a shift occurred in the mid-1960s, such that Anglo-American psychiatric reasoning sought to understand psychological problems through epidemiological studies, to help determine causes and related conditions, rather than speculate about individual cases (2013, 4). Such a shift in reasoning not only narrowed the focus of autism research to causation and intervention, but in doing so dismissed research on the potential variability in the way symptoms of autism present in children, further solidifying Kanner's case description as the profile for all autistic children. Thus, autism came to be dominated by basic scientific and clinical intervention research that presents the condition as a neurodevelopmental disorder. By assessing symptoms, etiology, prevalence, and developmental

trajectories, the aim of most research has been to identify neurobiological, cognitive, and socio-communicative processes characteristic of autism (Solomon 2010). This research set up a certain biomedical understanding of what autism is and how it is experienced. In investigating the neurobiological, cognitive, and socio-communicative characteristics of autism, the experiences of autistic individuals are understood in those terms.

Other scholars have questioned this biomedical understanding, suggesting that the origin of autism as a diagnostic category, in nature, can be interpreted as a nominal emergence rather than the appearance of a biological or medical condition. In this sense, autism is about the creation of a name category that differentiates certain kinds of experience rather than a psychological condition defined by cognitive and social behaviours. This interpretation draws on an understanding of the world where there is more dependence on "*what things are called* rather than on what they are" (emphasis in original text; Hacking 2006, 3). In creating new assessments and names for things, new things are themselves being created. Further, in the specific case of understanding people, this creative process also involves an evolution of certain knowledge through the interaction of the names of classifications, the people they classify, and the experts that classify them (Hacking 2006, 5).

Ian Hacking draws on Michel Foucault's work in developing and applying this methodological approach, which he refers to as dynamic nominalism, to his analysis of autism (Hacking 2006). A self-proclaimed historian of the present, Foucault can thus be retroactively interpreted as practicing historical nominalism. Rejecting a deterministic pre-given essence or nature, he interprets experiences, such as those of sexuality, within the specific historical fields that shaped them, and to an extent incited them, which both created and limited the form those

experiences could take at a given historical moment (Foucault 1994, xxxiv). In his case study of homosexuality, Foucault argued that this kind of person, 'the homosexual' exists only in a particular historical and social setting (Hacking 2006).

Rooting himself in Foucault's work, Hacking highlights dynamic nominalism as a tool for understanding autism through his concept of 'making up people'. The concept refers to the creation of categories as a way to understand different ways of being in the world. Hacking claims that prior to a certain understanding and creation of a category of experience, the people within said category did not exist (Hacking 1986, 7). In the case of autism, prior to the creation of the psychological diagnosis, there were no autistic people. Although individuals may have experienced what would now be described as symptoms of autism, there was no such name for them. Autistic people came into existence, in a sense they were made up, because a category distinguishing autistic experience from other experience was created. In relation to the increasing prevalence of autism in recent years, the strong version of Hacking's perspective would suggest that, in addition to more cases of diagnosis, the increasing recognition of autism as a category of experience plays a large role in inflating the rate of diagnosis.

As an example of its nominal emergence, autism can be understood as being constructed through medical discourse. The construction of this category from within the field of psychiatry relied on expert knowledge to determine what is "normal" and what is "abnormal". Particularly in the case of autism, as the symptoms of this conditions are predominantly behavioural or social as opposed to biological, much of the diagnosis of this condition relies on subjective assessment. Thus, medical authorities, in constructing autism in this way, have presented a certain conceptualization of autism, one that shapes autism as a medical disorder. Foucault argues that

this is how medical discourse constructs knowledge about the body (1976). Furthermore, he argues that such medical discourses influence how people behave and understand who they are, as well as their experiences with others. This also shapes the need for and what people understand as legitimate medical intervention (Foucault 1976; Conrad and Barker 2010).

Initially, I had set the term autism as a placeholder in my work, not wanting to impose some "thing" in a context where it may not exist in this form. However, I found that the term autism was present specifically in this form. There seemed to be an acceptance of the standards that Western biomedical expert knowledge had set to define "normal" and "abnormal". The first sign of this was evident in the full name of the Joy Centre itself, the Joy Centre for Children with Autism. Beyond that, all of the awareness materials applied the biomedical vocabulary associated with autism.

> **Autism** is a lifelong developmental disorder that affects the brain's function. The first signs usually appear before a child is three years old. People with autism often: find social interaction difficult, have problems with verbal and non-verbal communication, demonstrate restrictive and repetitive behaviour, have a limited set of interests and activities, and experience over- or under-sensitivity to sounds, touch, tastes, smell, light or colours. (*Nia Foundation Joy Center for Autism*, pamphlet)

This description is from a pamphlet offered, both in English and Amharic, in the front office at the Joy Centre. It continues on with specific terminologies, such as the autism spectrum and the sub-categories within it and the specific criteria for diagnosis. Many parents told me that they had initially heard about autism from television promotions (sponsored by the Joy Centre)

about the awareness of this condition. It is important to note that while the term autism is becoming more and more recognizable in Addis Ababa, I found that parents understood and spoke of what autism means in terms of the three markers at the core of this thesis: *aff meftat*, *mesmat*, and *terebishwal*. While certain kinds of experiences are beginning to be categorized as autism in Ethiopia, the understanding of those experiences are described in these three terms. I argue that this is indicative of a reframing of what is already understood to be "normal" and "abnormal" in this context, rather than a complete adoption of outside standards. Further, as there is no specific Amharic word for autism, there is also no descriptive derivative that can be used to describe the individual to which the condition is attributed. In other words, there is no way to describe someone as autistic and thus, in place of this, those with autism (particularly in the case of children) are sometimes referred to as *ye otizm lijoch* [lit. autism's children]. I think that the way this term autism has been manipulated to fit into the Amharic language parallels the way parents interpret the concept of autism as a biomedical condition to fit into their own understandings of their children.

An identifiable movement in relation to medical discourse is the rejection of traditional medical professionals as sources of expertise. A paramount example is vaccine hesitancy in the United States. Increasing rates of diagnosis of autism coincided with a moment of vaccine safety doubt in the late 1990s and early 2000s (Kaufman 2010, 13). The sense of vulnerability, doubt, and self-responsibility pushed parents to acquire their own (self-defined) expertise that allowed them to take action and care for their children in anti-biomedical ways, such as not having their children vaccinated due to a believed association with autism (Kaufman 2010, 20). In my research, the parental care-work, that is, the work of "caring for" one's children, that I am

interested in is evident in the very journey that brought parents to the Joy Centre. Many of these parents may not have had direct access to any medical expertise until they came to the Centre and instead they were developing their own expertise by way of their experiences trying to understand and care for their children. The behaviours they noticed in their children, the decision they made in bringing their child to the centre, and their daily struggle in coping with their child's condition, are all part of these parents' ways of knowing and working, enveloped in the process of caring for their children.

Caring for

I must clarify the way in which I am using the term "care". With recent medical and biotechnological developments, the work of care is reframed in terms of its political, financial, and ethical issues (e.g. availability of public and private care services, cost accessibility, etc.) (Fine 2005). The provision and availability of care is framed as a practical problem in response to existing forms of caring that prove inadequate or unsustainable, and for which new solutions are sought (Fine 2005, 248). The Joy Centre is positioned as a solution to the lack of appropriate care and education for children with autism. This kind of care occurs on a larger, systematic and structural scale, having much to do with the provision, the accessibility and the kind of care made available by Ethiopia's healthcare system. This framework of care as a practical problem emphasizes the relationship between knowledge and power, in that the development of medical and biotechnological knowledge allows for the evaluation of some forms of caring as inadequate. In the case of the Joy Centre, Zemi advocates for and applies her resources in establishing change in the kind of care available for children with autism in Ethiopia based on her individual

experience. As research on autism in Ethiopia is lacking, Zemi's trouble keeping her son enrolled in standard school is what pushed her to travel abroad and have her son assessed by doctors, only then receiving a formal diagnosis of autism.

"Caring for" others is often understood in a material sense, physically working, lifting or supporting to care for the other, and it can take a heavy bodily and emotional toll on the carer (Wilkinson and Kleinman 2016, 162). In fact, the Amharic translation of the word "care" highlights the bodily and emotional duality of this work. There is no single word for "care" in Amharic, rather it can be translated to *maseb* [lit. to think] or *metchenek* [lit. to worry]. This sense of caring refers to the inner emotional labour of caring for someone. For example, in the case of a mother caring for her son, to say *silesu tasibalech* or *titchenekaletch* [lit. she thinks about or worries about him] is meant to communicate a kind of constant care that is passing from mother to son in the form of emotional labour. In another sense, "care" can be translated in Amharic as *masadeg* [lit. to raise] or *menkebakeb* [lit. to cater to specific needs]. This sense better illustrates the physical work of caring for someone, such as feeding and cleaning.

According to Annemarie Mol, "Care is a process: it does not have clear boundaries. It is open-ended. ... care is not a (small or large) product that changes hands, but a matter of various hands working together (over time) toward a result" (2008, 18). While formal services and institutions of care for autism may be relatively new to Ethiopia, it would be wrong to assume that Ethiopian parents previously had no way to care for their affected children. Such systems of care, the collaborative work of many hands (whether among family, community, church), are likely so embedded in the routines of the everyday that they are normalized, to the extent of potentially being rendered invisible. The Joy Centre is one such site where a system of care,

geared specifically towards the children enrolled there, has been enacted. In my work, I refer to parents' ways of caring for their children in this sense. In this sense, the work of care is occurring on a much smaller scale and is a part of the parent and child's everyday experience. From the very decision to bring their child to the centre to the avoidance of certain transportation routes in the city to lessen the amount of social interaction their child is involved in, these decisions and actions are a function of the parent's way of caring for their child. In my work, when I refer to how parents care for their children, I am looking at what parents understand to be their child's needs or issues to be and how they choose to address or look after them. Notably, as the specific behaviours and socio-cognitive impairments have been introduced as autism in Ethiopia, the ways of knowing and working with, in other words caring for, children exhibiting such behaviours and impairments, are being transformed. A child who does not pick up his toys when told to is no longer understood as a disobedient child and therefore is no longer punished as such. Instead, the child is known as not understanding the appropriate response to the instruction which they were given and thus punishment or teaching discipline as one would a "normal" child is ineffective.

The Ethiopian Context

All of the discussed processes (making up, knowing, working, caring for) are shaped by the history, values and norms of life in Ethiopia. Ethiopia is one of the largest countries in Africa, with an estimated population of 99.4 million in the nation and 3.6 million in the city proper of the capital Addis Ababa in 2016 (World Population Review, 2016). This nation has a rich cultural makeup, consisting of over 80 ethnic groups, each with their own dialects and

customs. Also notable is a rich history of religion, particularly that of the Orthodox Church, which some claim dates back to the first century (Dumont 1958). Politically, Ethiopia's history has been dominated by changes in government occurring by force; first with the communist regime, the Derg, taking power in 1974 to 1991 followed by the Ethiopian People's Revolutionary Democratic Front (EPRDF), a coalition of regional and ethnic parties, that defeated the Derg in 1991 after a drawn out civil war (Di Nunzio 2017, 3). Ethiopia garnered outside attention and aid due to media coverage of the outbreak of famine and HIV/AIDS in the 1980s (Pankhurst 2002). There was an inpouring of financial aid and social services from various nations and international organizations in order to combat these problems. This history of pressing health issues, as well as Ethiopia's state as a developing nation, has led much research to be conducted in the medical and economic fields by various Non-Governmental Organizations (NGOs) and United Nations Agencies (Gaym 2006). More specifically, the focus has been on increasing health research in order to improve the quality and accessibility of health care. One such improvement is the establishment of the Joy Centre for Autism.

Much of the nation's formal health care services are located in the capital city, Addis Ababa, reserving these services for those in close proximity or those with the financial means to access them. With a limited institutional health care system, traditional indigenous medicine has remained a prevalent form of care to the present day (Gaym 2006, 57). Up to 80% of the population in Ethiopia uses traditional medicine due to the cultural acceptability of healers, the relatively low cost of traditional medicine and difficult access to modern health facilities (Kassaye et al. 2006). Teferi Gedif and Heinz-Jürgen Hahn found that "Ethiopian traditional medicine is composed of a number of specific skills, namely, the use of plants, animal products

and minerals as well as magic and superstition"; while "most practices and treatments in herbal medicine require specialists or professionals referred generally to as herbalists, self-care using plants is common" (2003, 155). The tradition of indigenous medicine has persisted at least in part because of its geographical and economic accessibility, particularly for those living in rural areas. Those with low literacy levels, high workloads and low access to formal health facilities are most dependent on traditional medicine (Gedif and Hahn 2003, 159). Mothers are most often the de facto healers of the family, treating any ailments with the resources available to them (Gedif and Hahn 2003, 155). Since the tradition of indigenous medicine is passed on from generation to generation, it becomes an immediate and valuable resource, particularly to mothers who don't have the means to access formal services. Also, education and age have a significant association with the use of herbal medicine: illiterate individuals and older residents are significantly more likely to use herbal medicine than literate and younger people (Gedif and Hahn 2003, 160).

While the traditional practice of herbal medicine has continued, Ethiopia's health system has undergone some development, in terms of increasing access to health services, by improving the quality of its institutions and facilities. Much of the medical literature on Ethiopia applies biomedical, epidemiological, clinical and health systems approaches and is geared towards understanding how to improve the current health system, in terms of practical considerations such as increasing the quality and access to health care. However the complexity of variables affecting health, including the cultural, environmental, social, political and geographical dimensions, makes many types of research that can impact health directly or indirectly quite difficult (Gaym 2006, 56). In this vein, research on autism is even more difficult. The lack of

awareness and the nature of autism as a condition that is predominantly observed through behaviors, that can be interpreted subjectively rather than through objective physiological measures, make it difficult for families and doctors to identify and report cases of autism. Compounded with cultural, social, political, and geographical factors, aspects such as personal beliefs and access to privately or publicly funded resources has altered the visibility of this condition in Ethiopia. The result is a lack of statistical information about the prevalence and rate of diagnosis.

Various academic institutions, including the Addis Ababa University, Jimma University, and Gondar University, are the primary undertakers of health research in Ethiopia (Gaym 2006, 58). In collaboration with external institutions, there have been efforts to develop study bases in rural regions for the purposes of health research. Despite these efforts to ameliorate the state of health care in Ethiopia through research (joined to government efforts to establish a tiered network of health posts, stations, centres, and hospitals) the actual distribution of healthcare services is limited, with very little available especially in rural areas and it is often of poor quality (Girma et al. 2007). In 2005, there were 600 Health Centres, 1662 Health Stations and 4211 Health Posts mostly owned by government, which were estimated to cover 43% of the population at the time, estimated at 73 million (Girma et al. 2007, 216). Over the past decade, the Government of Ethiopia has given priority to the expansion of these health facilities, significantly increasing the number of health facilities in communities throughout the country. Between 2005 and 2013, the number of small health posts or clinics nearly quadrupled from 4,211 to 14,416, the number of health centers increased to 3,245, and the number of public hospitals grew to 127 (World Bank Group, 2015; Borgen & Dover, 2017). While this has led to

improvements in health service coverage and utilization of services at all levels, providing quality services remains a major challenge (African Health Observatory, 2010). Since specialized services such as the Joy Centre provides are still quite limited in rural areas, families may travel great distances or even relocate to Addis Ababa (evidently this limited to those who have the resources to do this) in order to access these services. It is also safe to say that much of the new knowledge about autism is located in the capital. Most parents who bring their children to the Joy Centre are from the capital itself and only happened to hear about the services offered there through word of mouth. Media promotions for the Joy Centre and awareness of autism is increasing so this newer knowledge of autism may be travelling outside the capital, but likely not far beyond major city centres.

Religiosity

Religion is a significant part of being Ethiopian for most of the population, in terms of beliefs, rituals, and identity. The majority of Ethiopians belong to the National Orthodox Church (with growing numbers of Protestants, Muslims, and Catholics). Health is seen as a 'gift of God' or 'the will of God' and many Ethiopians generally believe that their religion helps keep them healthy. The protection and promotion of spiritual well-being is tied to the protection and promotion of physical, social, mental, and material well-being (Kassaye et al. 2006). In this context of religiosity, "medical intervention can take various forms, such as the use of medicaments, the propitiation of causal agents through sacrifice and prayer, and changes in diet and regimen" (Young 1980, 105). Anthropologist Allan Young conducted research on medical beliefs and traditional medicine, with a particular focus on spirituality and possession, in northern regions of Ethiopia in the 1960s and 70s. According to his work, in the process of

understanding a sickness a phenomenon called symptom perceptualization can occur, "when people believe that a particular behavior or physical sign is a feature of sickness, but recognize this feature only as a concrete and discrete element divorced from the disease entity in which biomedical knowledge incorporates it" which may propagate a religious or spiritual interpretation of the symptom. In the case of autism, some children are nonverbal which has been historically perceived as distinct from a biomedical condition and interpreted as spiritual possession (1980, 108).

One might expect that in Ethiopia spiritual and religious beliefs would compete with medical discourse. However, I found that, while some tension still exists between holding these religious beliefs and accepting medical discourse, many parents at the Joy Centre seemed to have found a way to reconcile their identities as religious individuals with a degree of acceptance of the medical framing of autism, as this acceptance serves to justify their choice to bring their child to the centre for the services offered. In most cases, religious rituals such as praying, going to church, and drinking or bathing in holy water are still frequently practiced by Orthodox Christians and Muslims (Kassaye et al. 2006).

Although such beliefs were not evident among the parents I encountered, historically many Ethiopians have also participated in pagan (non-Christian) beliefs and rituals, in which certain spirits are believed to have the ability bring and alleviate illness (Kassaye et al. 2006). Further, the occurrence of a prolonged unexplainable illness, particularly those without physiological causes, such as autism, have sometimes been considered a sign that a spirit is seeking to possess an individual (Hamer & Hamer 1966). Hamer and Hamer worked in Ethiopia in the 1960s, and while their published work is now over a half century old, that does not mean

this way of thinking has disappeared or that it has not shaped people's present beliefs about spirit possession. For example, the idea that the devil can cause certain illnesses while God or traditional spiritual healers (i.e. witchdoctors) can provide healing is still applied particularly to mental illnesses and other conditions that are relatively more obscure or difficult to treat (Kassaye et al. 2006, 129). Witchcraft can be considered a set of beliefs that, regardless of truth, could reveal something about social relationships. When one steps outside the problem of true and false, witchcraft and spiritual interpretations of abnormality constitute a symbolic device for understanding difference and producing specific therapeutic effects (Favret-Saada & Cullen 1989, 41). Looking back, such a system of beliefs may have developed in part to fill a need for knowledge or understanding. While different Ethiopians from different regions conceptualize spirit possession and witchcraft differently, the use of spiritual discourse was present but not a direct frame for the way parents understand autism.

Different understandings of autism implicate different ways of speaking about autism. In the past, scientific or medical language has been characterized as cognitively meaningful while religious language has been considered emotively meaningful (Holmer & Holcomb 1961). An explanation using medical language focuses on the constituent circumstances of a phenomenon, such as the symptoms of autism, and then discloses the universal relations or laws by which these circumstances come to be as they are (i.e. develops diagnostic criteria by which autism can be defined) (Holmer & Holcomb 1961). I would argue that such a stark distinction does not hold true in the present as this would imply that religious language may be somehow inferior for its lack of reasoning and judgment. This distinction would also indicate that these languages do not interact or overlap in any way. It is important to consider that the interest in and intrinsic value of

traditional Ethiopian medicine cannot be only attributed solely to the lack of modern medicinal services. Even in cities where modern health services are more accessible and specialized, many people continue to go to traditional healers due to the cultural acceptability of and respect for healers and their easy accessibility (Kassaye et al. 2006). According to Young, a sick person's aim, regardless of whether they consult biomedical or religious intervention, is medical and his or her ultimate goal is to find a cure. The choice between physician, cleric-healer and shaman is founded on epistemological grounds (Young 1980, 113). Particularly as it relates to pagan beliefs about spiritual possession or Christian beliefs about punishment for one's sins, religious languages at one point dominated the way autism (rather what we now call autism) understood. All though these languages may still be dominant in rural areas, with the newer knowledge of autism located primarily in Addis Ababa, parents explain that these specific religious interpretations are fading.

Mothering

Although it was not anticipated and therefore not properly addressed in the questions I ask, it became apparent that mothering was a significant part of how autism was understood in Ethiopia. To be clear when I refer to mothers, I mean not only the person who gave birth to the child. Anthropologist Maya Mayblin, who explored motherhood in northeast Brazil, refined her definition of mother simply to mean the person that shelters and nurtures the child throughout his or her childhood (2012, 243). "Motherhood, in local parlance, is not necessarily synonymous with biology. What it must equate with, however, is that long, drawn-out process of love and care usually undertaken by one adult in particular once a child is out of the womb" (Mayblin 2012, 243). In Ethiopia, In the community at the Joy Centre, not only were the involved parents

predominantly biological mother but, all of the teachers were women as well. I found that there was an overlap of maternal characteristics between mother and teacher. While the centre presents as a school in form, in practice the kind of care that these teachers were providing puts them in a unique position. Beyond the role of educator, teachers had the responsibility of feeding and disciplining the children. As well, with the amount of time the children and teachers spend together and the sensitivity and specificity of the children's needs, the teacher roles themselves (this was expressed especially by those who had worked at the Joy Centre the longest) overlapped with the role of mothers in sense of the tender and nurturing care they were providing.

In addition to these intimate relationships of mothering between the teachers and students, the fact that the majority of parents involved at the Joy Centre are mothers is especially significant. That the responsibility of childcare is undertaken almost completely by mothers speaks to the structure of and values held within the Ethiopian family unit. This element of mothering itself is one worthy of exploring for the way that these women's actions shape and embody existing knowledge, in this case, by becoming experts of a certain kind through their experiences.

Parent Activists

In order to consider how science and medicine are "making knowledge" about autism in Addis Ababa, I have observed the agents in this movement to be parents. The Joy Centre itself is a nonprofit, non-governmental organization, established by Zemi Yenus (Mulat 2016). Zemi is the mother of an autistic child herself and it was her own experience, struggling to find care and

education resources for her son, that propelled her towards founding this centre. Zemi's actions and motivations position her as a kind of activist in this period of moving knowledge. When I use the term activist I refer to Zemi and other parents and family members in the sense of their involvement in disseminating new knowledge about autism, engaging in new forms of educating and caring for autistic children (in the sense of programs offered at the Joy Centre), creating counselling and support services for parents, as well as negotiating with government, policy makers, international donors, and relevant professionals for the purposes of bettering access to care and deconstructing the stigma surrounding the condition (Mulat 2016).

This sense of activism is rooted in the context of biomedical and scientific progress, particularly in 19th and 20th century Europe and North America, through which individuals increasingly understood themselves in biological terms (Rose & Novas 2004). New knowledge is deeply and intricately constructed, involving multiple instrumental, linguistic, theoretical, and organizational frameworks, along which a system of symbolic conceptions is developed, and by which people can communicate, perpetuate, and develop their knowledge about attitudes towards life (Knorr-Cetina 1999, 10). Over this period of 19th and 20th century scientific progress, life emerged as a political object and with it a new kind of political struggle, wherein one could push back against the way life is governed in the name of claims to a 'right' to life, to one's body, to health, to the satisfaction of one's needs (Rabinow & Rose 2006, 196). The languages of biology, particularly medicine, have shaped the ways in which individuals understand themselves and relate to themselves and to others. These biological senses of identification and affiliation made certain kinds of ethical demands possible: demands on oneself; on one's kin, community, and society; on those who exercised authority (Rose & Novas 2004, 441).

Rose and Novas suggest that endeavors to educate the public about science and technology are ways of "making up" the biological citizen (2004). By "making up citizens", they refer to the reshaping of the way in which persons are understood by authorities, be they political, medical, legal authorities or otherwise (Rose & Novas 2004, 445). Persons are understood in terms of created categories, such as the chronically sick, the disabled, the blind, the deaf, or in my case the autistic child in Ethiopia (Rose & Novas 2004, 445).

Considering this, parents' choices are also a kind of activism. In a society where awareness of autism and access to education and care services are still in their early stages, the parents that are able and choosing to seek out care for their children are, in a sense, propagating change. Beyond the kind of activist listed above, I frame the activist subject through the ideational elements that characterize everyday activist life (Lee 2016). In other words, I am looking at the Ethiopian parent as the activist subject in terms of their conceptualizations of autism that shape their everyday actions and choices as to how they will care for their autistic child, which on a larger scale may contribute to the development of increasing access to care services, raising awareness, and destigmatizing autism by positioning certain behaviours as a medical condition.

In the first chapter of this thesis, I begin with the first concept of my framework, a tied mouth. Although it is an existing marker of difference with historically religious interpretations, parents are now recognizing a lack, or regression, of verbal ability as part of the conceptualization of autism. Beyond simply accepting this solely as a symptom of a biomedical diagnosis, the way parents speak of this marker is indicative of their integrative understanding (including both biomedical and experiential knowledge) of a certain kind of experience that is

now being categorized as 'autism's child'.

In the second chapter, I move to parents' conceptualization of listening, or more specifically not listening. 'Autism's child's' inability to listen is experienced, by the parent, as a missed expectation of obedience that embodies their struggle to relate to their child. Their experiences have shown them that they cannot expect that their child with autism will listen. However, instead of framing their child as disobedient, they look to understand and find ways to adjust their expectations. In another sense, they are shaping the ways they can relate to their child.

For the third chapter, my focus is the incidences of inner disturbance that parents describe as *terebishwal*. Children with autism often experience what looks like a ‘meltdown’ (increasingly loud verbal stereotypy, aggressive outbursts in the form of repeatedly hitting oneself or others) for seemingly no reason. In western literature, these meltdowns have been attributed to a hypersensitivity to sensory stimuli. But for the parents at the Joy Centre, they understood these incidences as indicative of some internal emotional processing that their child was going through, which rather than sensing is a kind of social sensibility.

Chapter 1. "*Aff alfetam"* [lit. he has not untied the mouth]

A "Tied Mouth": the emblem of pathology in 'autism's child'

"*Ye otizm lij* [lit. autism's child] and a normal child cannot compete."[5] I was asking a parent what kind of resources are available to children with special needs at public or private schools and this was part of their answer. Most schools do not have a separate class or teachers equipped to educate children with special needs so, as this parent described it, children with autism are left behind because they cannot keep up with the pace of the 'normal' children. Although the use of the word 'compete' implies a hierarchy of achievement, and while that is highly apparent and valued in the education system in Ethiopia[6], what this parent was focused on was the difference in the kind of care and education children with autism need and advocated for the awareness and development of institutions, like the Joy Centre, that work to meet those needs. Ultimately, this parent was expressing some fundamental difference between children with autism and 'normal' children.

The three concepts I am working with to illustrate parents' understanding of autism in Ethiopia are based on behavioural markers that parents have identified and recognized as a sign of something 'not normal' about their children. In the retelling of their experiences, the way parents describe the significance of these behavioural markers gestures to some parameter that

[5] Conversations and interviews held in Ethiopia, quoted in this work, were originally held in Amharic. In translating their words, I choose to leave certain words in Amharic because the words themselves communicate something significant that requires analysis.

[6] Over the course of my fieldwork, I heard many peripheral remarks about the competitive nature of the education system, both public and private. The 'better' the school (in terms of quality of teachers, resources available to children, etc.), the higher the expectations held of the students, namely in the form of grades. I believe this competitive quality of education is a fundamental part of the parents' narratives towards understanding autism as many of them noticed that their children were having significant behavioural and/or academic issues at school.

defines what it means to be a 'normal' child. Children with autism are outside those parameters. Even the parent's wording above, "*Ye otizm lij* [lit. autism's child] and a normal child cannot compete.", plays on an implied dichotomous conceptualization of normalcy. The child may be either normal or not and, in the case of children with autism, they are not.

In this chapter, I look critically at the way parents understand their children by addressing the significance of *aff meftat*, the untying of the mouth, as part of my conceptual framework for parents' understandings of autism. Specifically, I argue that the child's lack of or regression in verbal ability, which Ethiopian parents spoke of in terms of the untying of the mouth, is emblematic of pathology for these parents, particularly as it is the primary descriptor of 'autism's child'. This idiom refers to the typical developmental point where a child first begins speaking, an occurrence that parents expect when the child reaches two to three years of age. The lack (or regression) of this step is a key indicator of difference, particularly in the case of autism since lacking (complete or some degree of) verbal ability is a central criterion for diagnosis. As a part of my analysis, I work through parents' experiences to deconstruct the significance of a 'tied mouth', the role of this marker in making up 'autism's child'[7], and the integrative work parents are doing to form their understanding of autism based on their existing ideas of normalcy (including traditionally religious interpretations of possession) and the newer knowledge of autism being introduced to them by the Joy Centre.

[7] Note: I use quotes when referring to 'autism's child' not to delegitimize the personification of this condition in this way. Rather, I mean to remind myself and the reader that this term is a translation of a phrase plucked from the shared language of parents and staff at the Joy Centre.

Recognizing autism in Addis Ababa: the visibility of pathology

The first three weeks that I spent at the Joy Centre, volunteering as a teacher's assistant in the Occupational Therapy class, were a kind of transformational period for me. When I came to the Joy Centre, I thought of myself, a Canadian of Ethiopian descent, as in some part "native." I was regarded as another Western world researcher looking to help the needy, however, and consequently, I was treated as such. At first, this discernibly filtered my interactions with the staff and parents in the community.

I noticed my conversations with the teachers and parents being geared towards how autism is treated in the West. Teachers would ask me about the kinds of therapy programs used in Canada or the United States and how they were implemented. Parents would ask me about the kinds of improvements I had seen in my own experience working with children with autism in Canada. I even received a few questions from parents about whether I had ever worked with a child who was no longer autistic, 'cured' in a sense, and how long that had taken. Especially in my conversations with the parents, I noticed that most would initially downplay the significance of their experiences, of their efforts in caring for their child.

However, over the course of those first three weeks, something changes. I am included. The children recognize me. They come to find me during their breaks. They are affectionate in their own way. A few come over to give me hugs or 'high-fives', others just sit beside me. The parents have also warmed to me. They make a point to say hi to me when they see me, tell me stories about their day, or even suggest things for me to do in the city. The power dynamic shifts and some of the parents even come to regard me as a confidant.

One afternoon, as the children played during their final break period before the end of the day, I was sitting with Ruth, one of the mothers who brings her child to the Joy Centre. As we watched the kids, Ruth was telling me more of her story, her struggles caring for her son. At one point, she looked to me and said, "You know, it was not born with him. He was fine at first, until he was three years old. Then one day, he fell." A few days later, she noticed a change. Ruth's comment was a defiant confession in a way. Autism is known to be a condition with no specific cause. The head staff at the Joy Centre make an effort to educate parents on this. In a sense, it is reassurance that they had done nothing wrong, that there was no way for them to prevent this condition. The Centre itself has an area in the main house that is stocked with pamphlets and flyers explaining the condition in these terms, along with information on its symptoms, prevalence, and treatment. Most parents that I had spoken to up to this point expressed this understanding. They knew that there was some unknown element embedded in this condition and chose not to dwell on it. The more I spoke with Ruth, however, the more she expressed that this explanation of autism was not enough. It did not explain why her child, who was totally healthy and 'normal' before, suddenly changed so drastically.

> "He used to talk and play all the time. He would even go to the neighbour's house to play then come back home. He would call all the neighbours' kids by their names. *Afun feto neber, yinager neber* [lit. He had untied his mouth, he used to speak]. *Ande ken, aynun iyesekele, jorounim zegaw, afunim aserew, aynum tebelashe* [lit. One day, while he was staring upwards, it closed his ears, it tied his mouth, his eyes were ruined]."

Ruth's experience of autism allowed for an explanation as to what was causing her son's behaviours. Autism was. It was autism that tied her son's previously untied mouth, that closed her son's previously open ears, and that ruined her son's perfectly fine eyes. In describing her

son this way, Ruth was not referring to any physical change in her son. Rather, she is referring to an internal change. As she spoke of her son's tied mouth, we could hear him laughing and screaming with the other kids. But an element of communicating 'normally' was missing. Further, her son was neither deaf nor blind. But his ability to listen the way he used to, the way he should, was gone and he instead developed a habit of fixating on specific visual stimuli. Thinking of autism as the tier of mouths and closer of ears allowed for some understanding of what was happening to her son. But, to accept that there was no initial triggering cause to this condition in her son made no sense to Ruth. It did not explain how and why her relationship with her son had changed in the ways it did. She could not talk to her son the way she used, nor did he listen to her the way he used to. So instead, believing that her son had been 'normal' and was only afflicted with this condition after a triggering fall, allowed her the hope of her son 'returning to normal' one day. She credits the care he has received over the past two years, and continues to receive, at the Joy Centre as the main reason why he is 'getting better'. "Now, he can speak. His ears listen. His mind is a little behind but he is coming back. In fact, when you see him, you would say it is not autism. When people see him, it does not show."

Parents' recognition of some fundamental difference in their children is what initially leads them on their journey to the Centre, and their conceptualization of autism is rooted in this. They recognize that something about their child is not 'normal'. In seeking answers and a way to care for their child, parents negotiate the health, social and economic systems around them. As these systems in Ethiopia are fairly ill-equipped to provide the answers and services that parents are looking for, I argue that parents develop their own answers that they later integrate into the answers given to them by these larger systems. Ruth remembers the exact moment she noticed a

drastic shift in her child. Even though, she was later given a different explanation for this shift, it made more sense to her to keep her original understanding of what had happened and work with the newer information she was given at the Joy Centre. While Ruth's understanding of her experiences are obviously unique to her in one sense, in another, her story reads like many of the other parents I encountered at the Joy Centre. Ruth's insistence on the fall that triggered her son's condition reflects the way that parents do not simply accept the "Western version" of autism, instead they work to integrate new information into the stories of their lives based on what they know, as well as a hope for the future. This work of integration is what I am referring to in a later section as I discuss the way 'autism's child' is made up and recognized as a distinct person for Ethiopian parents. Before moving to understand 'autism's child', I will first work to deconstruct the significance of a 'tied mouth'.

What is a "tied mouth"?

When parents used the phrase 'autism's child', I could sense a kind of weightiness in the way they believed this condition impacts the child, that in belonging to autism the child no longer belongs to the parent. Autism intervenes in the parent-child relationship on a fundamental level. Further, in understanding how autism intervenes in this relationship, parents spoke exclusively in terms of behaviours. Autism's influence on the child manifests itself as a certain range of behaviours. This interpretation works as a useful tool for parents because while the fact that the child exhibits these behaviours is still considered problematic, illustrating autism in this way (in behavioural terms) gives space for the idea that these behavioural problems can be remedied through the application of behavioural therapy programs, which is what the Joy Centre

advocates. In other words, this interpretation includes room for the child to potentially achieve 'normalcy'. Essentially, I propose, this is the work that parents do to integrate their own understandings with this new knowledge of autism, to which they have been relatively newly introduced.

Over the course of my time in Addis Ababa, many parents told me about their unique experiences and journeys before coming to the Joy Centre. As I listened, I noticed overarching similarities in their stories. For example, when Alem, one of the mothers with a son at the Joy Centre, described her experience of when she first recognized something was wrong with her son, I heard the significance of a 'tied mouth' that I heard in many other stories:

> I didn't know my son had any problems until he was three years old. Physically, when you look at him, nothing different shows. He hadn't started talking yet, but some kids start later than others, you know. The rest, he was the same as the other kids. The way he walked, the way he cried. But he was quiet. He would only watch cartoons on TV. That's all he wanted to do, so I would get him more DVDs to watch cartoons. Everyone would tell me how lucky I am because of how quiet and disciplined he is. But I didn't know he had a problem.

Most parents told me that whether or not a child begins speaking, or "untying the mouth," at the appropriate age is significant, and, in their cases, initially marked that something was different. This phrase is a derivative of the Amharic idiom *aff meftat* which literally translates to "untying the mouth". This idiom refers to the point in a child's typical development that he or she begins to speak. In terms of typical child development, children begin babbling and uttering their first words (e.g. mama, dada, doggie, etc.) within their first year. At this point, the child would be described as having "untied his/her mouth". After that point, the child usually begins to form simple sentences to express their desires (e.g. give me, want that). Often times, the first

indicator of autism is when children experience what is sometimes described as speech regression. After having begun babbling and perhaps even using words and simple sentences, these children appear to lose their ability to communicate verbally. In the West, this is typically observed between 2 and 3 years old. In my time at the Joy Centre, most parents told me they noticed this change when their child was around 3 years of age. They told me that they had expected their children to move past babbling into speaking words, forming partial sentences around 2 or 3 years old. While some parents admitted to being concerned when their child had not started talking around age 3, others said they dismissed this concern with the same justification: some kids simply started speaking later. Some indicated that they had not thought their child's lack of verbal communication to be a problem until 5 to 7 years of age. One mother, in particular, explained to me that she was living in Saudi Arabia when she gave birth to her son. It was not until her son reached 6 years of age while still not having developed past babbling that she became concerned because she had heard children in that region sometimes develop language more slowly. Some only "untied their mouths" at age 8 or 9. Yet, at some point, this justification becomes insufficient and the parent feels the need to have their child seen by a doctor or ask around for information.

Alem said she asked around and took her son to a doctor just to be sure of what was going on with him.

> We heard of Dr. Ayele at a clinic in Bole. I took my son there. They looked at this head, they scanned him, did an MRI. They looked at his behaviours, like when he gets angry, he screams and cries and hits himself. They saw that these were *ye otizm baharioch* (lit. autism's behaviours) and that he was *ye otizm lij* (lit. autism's child).

Many parents described one such behaviour of autism's as "*afun aserew*" which translates to "he tied his mouth"[8]. The 'tying of the mouth' is perhaps the most significant behaviour of autism's. For parents, a fundamental element of their relationship with their child is severed. A certain kind of loss is felt because their child cannot communicate with them 'normally'. Further, a large part of parents' struggles is understanding what their child needs and how to care for them while not being able to get an answer from their child directly.

In Western contexts, this symptom is referred to in terms of verbal ability. Children that fall within the range of symptoms that comprise the Autism Spectrum Disorder can vary greatly in their ability to communicate verbally. The more severe end of this symptom is perceived in children who are non- or minimally verbal. In some cases where children are described as non-verbal, these individuals lack all spoken language: their vocalizations only include atypical nonspeech sounds and some vowel approximations (i.e. grunting sounds or repetitive syllabic sounds, e.g. *deedeedeedeedee*) (Tager-Flusberg & Kasari 2013, 469). In the case of minimally verbal children, their expressive language is extremely limited with just a few words or fixed phrases (e.g. *want that*) used infrequently and only in limited contexts. Other children included in this group may have some spoken language, but they are primarily echolalic (i.e. repetition of vocalizations made by another person) or use stereotyped or scripted language in ways that appear inappropriate and non-communicative based on the social situation (Tager-Flusberg & Kasari 2013, 469).

[8] Much like in Ruth's earlier words, when parents used the personified sense of autism, autism would be grammatically masculine. In Amharic, most often language is skewed towards the masculine and therefore, I feel it would be imprudent to assign great significance to the occurence of this in this case. However, I will say it does colour the parents' illustration of autism in an interesting way.

These nuances in understanding verbal ability as a symptom of autism in the West are not so apparent among Ethiopian parents. As I mentioned, for the parents at the Joy Centre, the conceptualization of the child belonging to autism, manifesting in the form of specific behaviours, is useful as it grants parents a way to incorporate this new knowledge of autism that the Joy Centre advocates, by way of making the behaviour-focused programs at the Centre a logical and appropriate form of care. The idea of 'autism's child' is a tool in the work of integration, of their own understandings and this new knowledge, that parents are doing. Notably, this work is still in progress. As illustrated by Ruth's story above, parents hesitate and struggle to accept the Western biomedical conceptualization of autism. Evidently, in the West, the subtle distinctions in verbal ability (such as echolalic or stereotyped language) are a result of authoritative biomedical definitions of autism that have been developing, arguably, since Kanner's observations were published in 1943. It may be that these distinctions in verbal ability are not significant for Ethiopian parents. Echolalic or stereotyped language still intervenes in their parent-child relationship but perhaps, just as in the case with non-verbal children, this is just another way that autism 'ties the mouth'.

The primary diagnostic authority used to define autism, in Canada and the United States, is the Diagnostic and Statistical Manual of Mental Disorders (DSM), as it is produced by the American Psychiatric Association. In its most recent and fifth edition (DSM-V, 2013), autistic disorder, Asperger's disorder and pervasive developmental disorder not otherwise specified coalesce to form the diagnosis 'autism spectrum disorder'. Within this spectrum, there are no specific criteria distinguishing those who can be described as non- or minimally verbal. The DSM-V includes stereotyped speech (e.g. echolalia, idiosyncratic phrases, etc.) under criteria B:

restricted, repetitive patterns of behaviours, interests or activities (American Psychiatric Association, 2013). Diagnoses of autism are now all the more variable due to the combination of three previously distinct disorders presenting as one. Essentially, any of the symptoms can present at any severity within one individual. In other words, a child with any range of other symptoms at different severities may present as non- or minimally verbal, making it difficult to account for the cause of this symptom altogether.

The International Classification of Diseases (ICD), produced by the World Health Organization (WHO), followed suit and streamlined the current diagnostic criteria for autism under the umbrella autism spectrum disorder (Zeldovich 2017). In its current edition (ICD-11, WHO, 2018), the diagnostic criteria for autism is based on persistent deficits in social interaction, communication and behaviours. It is further subdivided according to the presence or absence of disordered intellectual development along with either mild to no impairment of functional language, impaired functional language or the absence of functional language. The criteria for these subdivisions in qualitative abnormalities in communication are nuanced as such:

> (a) … there is only mild or no impairment in the individual's capacity to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.
> (b) … there is marked impairment in functional language (spoken or signed) relative to the individual's age, with the individual not able to use more than single words or simple phrases for instrumental purposes, such as to express personal needs and desires.
> (c) … there is complete, or almost complete, absence of ability relative to the individual's age to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.
>
> (6A02.0; 6A02.2; 6A02.4, ICD-11, WHO, 2018).

These are only general variations of this symptom of autism, one of which needs to be present in concert with varying degrees of impairment in social interaction, communication, behaviours, and intellectual development. Older statistics suggested that over half of all children with autism failed to acquire spoken language [National Research Council, 2001]; however, more recent studies suggest that this figure is now lower, at around 30%, in part because more children are now identified as having autism and in part because of earlier diagnoses as well as greater access to more effective early interventions that significantly improve spoken language and communication skills in younger preschoolers with ASD, thus potentially preventing them from remaining nonverbal at later ages (Tager-Flusberg, Paul, & Lord, 2005) (468).

A significant difference between the DSM-V and the ICD-11 is the DSM-V classification of stereotyped speech under a behavioural criteria, contrary to the ICD-11 which distinguishes language from social impairment. In a sense, this behaviour-focused classification works with Ethiopian parents' conceptualization of autism. I would hesitate to say that this is purely evidence of the way the DSM-V classification has shaped parents' understanding of autism as I would credit parents for knowing and recognizing the behaviour of a 'tied mouth' as a marker of something not 'normal', based on their existing ideas of normalcy and the historical interpretations of this abnormality. Instead, I suggest this is evidence of the integrative work parents are doing to form their understanding of autism. A behaviour-focused classification points to behaviourally oriented interventions such as the programs at the Joy Centre, a key site for this integrative work. Further, although the ICD-11 allows for a more organized breakdown of different autistic profiles according to verbal ability, I propose that perhaps these distinctions would not necessarily translate for Ethiopian parents as they focus on "instrumental purposes",

without adequately distinguishing different levels (from impairment to absence) of functional language and those intervenes in social spaces (such as a parent-child relationship). I make this proposal with an eye to the reality that the majority of the children at the Joy Centre have severe deficits in verbal ability. As non-verbal children are highly challenging to care for (and often cannot attend regular school), they are often classified as high-priority in terms of admission to the Centre. Thus, almost all the parents I interviewed had children who were non- or minimally verbal. Although I did have conversations with the parents of children with milder severity, a more in-depth analysis of their stories would be required in order to better understand how those parents work to integrate ideas of an 'untied mouth' with this newer knowledge of autism.

Untying the mouth

One particularly significant story I was told by many parents and teachers was that of Zemi and her son, Jojo. Zemi Yenus is the founder of the Joy Centre and it is her personal experience that drives many of the parents. Back before the founding of the Joy Centre in 2002, Zemi was a hard-working mother of two sons having trouble understanding why her youngest son was not developing the same as his older brother. Zemi took him to be tested in the UK and she was told he had autism. With resources and care for autism being practically nonexistent in Ethiopia at the time, Zemi developed a teaching method to help her non-verbal son. Based on the Ethiopian alphabet and sounds, Zemi developed "Abugida Fonetiks", a method based on applied behavioural principles that combines sounds and visualization to help a child learn to speak, write, and read (Said-Moorhouse & Wangondu 2015). Zemi had started teaching her son when he was eight years old and by the time he was sixteen, Jojo told her "love you, mama"

(Said-Moorhouse & Wangondu 2015). Zemi's story is significant because it became an iconic version the narrative of 'autism's child', one wherein the child's 'tied mouth' is 'untied'. In this telling of the story of 'autism's child', an alternate ending is presented for children who were previously viewed as hopeless without divine intervention. Not only does Zemi's story make an alternate future possible for these children but her experience also gives hope to parents that, as indicated by Jojo's iconic words, they may one day have a 'normal' relationship with their child. Although the reality of this possibility is unreliable, as there is no evidence that indicates a way to guarantee that a non-verbal child will regain, or develop, verbal ability, Zemi herself as founder of the Joy Centre has been elevated to iconic status. She not only paved (and is continuing to pave) the way for social and educational advancement but she is also making basic survival possible for many of the parents at the Joy Centre. A large proportion of the parents with children at the Joy Centre (some of which Zemi takes on pro bono) would not be able to work if they did not have some place to take their child every day. In essence, Zemi is a role model (in part due to her experience, in part due to her benevolence) and so her story circulates among the parents as a blessed potential. Anthropologist Roy Richard Grinker addresses this phenomena in his global analysis of autism. He references Lionel Gossman's work on historiography that "evidence only counts as evidence and is only recognized as such in relation to a potential narrative, so that the narrative can be said to determine the evidence as much as the evidence determines the narrative" (1989:26) (Grinker 2010, 177). In this case, even though Zemi's story is not technically a reliable possibility for most parents, this single instance of the best possible scenario created a hopeful potentiality that incited a positively-skewed feedback loop. Notably,

much like a prayer, parents spoke of Zemi's story not necessarily as a guaranteed example of their future but as an earnest hope for their future.

In this section, I discussed how parents' recognition of a 'tied mouth' is a part of their interpretation that autism intervenes in the parent-child relationship, and that this intervention manifests itself as a certain range of behaviours. I suggest that this marker of the 'tied mouth' is a significant part of the conceptualization of 'autism's child' as this interpretation is a useful tool for the work that parents are doing to integrate their own understandings with the new knowledge of autism as a diagnostic category. In the next section, I work clarify the way in which this marker contributes to making up 'autism's child'.

Making up 'autism's child'

"What is the difference between autism and autistic? One is the illness and the other is the child, right?" one of the parents at the Joy Centre asked me. This was one of the only times I heard the word "autistic" used in my three months in Ethiopia. But it impressed upon me something I had been hearing in different ways, the marking of a specific distinction between the child and autism. That parents colloquially take up the noun form in the phrase 'autism's child' gestures to how parents understand and envision the child that falls under the category of autism. In psychology, diagnostic labels are a means of distinguishing and categorizing different experiences of the world that are accepted as deviating from normal. From a medical anthropological perspective, the labels themselves are objects of analysis. Ian Hacking approaches autism in this sense, by taking up this category to understand its relation to those placed within it. His concept of 'making up people' allows for an analysis of autism as a

category that was created to understand a different way of being in the world. Moreover, he notes that the individuals within this category can only be acknowledged, and, in a way, have only existed, since the creation of this category (Hacking 1986). In other words, the existence of autism as a category is what brings into existence individuals that are autistic. Further, while the diagnostic label and category of autism has travelled from the West to Ethiopia, the community at the Joy Centre (the parents in particular) is making up what autism means and who 'autism's child' is in relation to their histories, knowledge and worldviews. The basic tenet that autism is a deviation from normal is accepted but as parents work to understand and care for their children, defining the parameters and significance of pathology in relation to a normal is a process they are engaging in.

This is not to say that the qualities characteristic of autism did not exist prior to the creation of this category. Rather these qualities were understood in their own right until a configuration of them became known as autism. In the context of Ethiopia, the continuous increase of enrolment at the Joy Centre is less indicative of global increases in the diagnostic rates of autism (see Introduction to this thesis) than the introduction of autism as a category and hence the potential to recognize people, specifically children, who fit this category. Again, this is not to say that the qualities that make up the category of autism did not previously exist in Ethiopia in their own right. Rather the specific constellation of qualities called autism was not yet recognized. The three key qualities at the core of this thesis are not necessarily new to the parents at the Joy Centre but they are now recognizing these elements together under the umbrella of autism. These key qualities take the form of the specific behaviours that parents talked about. The parents' focus on behaviours is in itself significant to the way they

conceptualize this condition. Rather than build on biomedical (i.e. cognitive) markers, parents dwell on specific behaviours because these behaviours are what make autism visible. Further, not only is autism made visible but the children 'belonging to it' are made visible as well.

Hacking's argument is founded on the principle that prior to a certain understanding and creation of a category of experience, the people within said category did not exist. In this case, prior to when autism was "discovered", and the psychological diagnosis was created, there were no autistic people. The creation or making up of people occurs as these categories make changes to the space of possibilities to personhood (Hacking 2007, p.165). Similarly, in Ethiopia, while individual behaviours were considered markers of difference or abnormality, these behaviours did not necessarily belong to a recognizable distinct category. Autistic people (children in particular, in this case) were made up because a category, grouping and distinguishing autistic experience from other experience, was created.

Hacking distinguishes between strict nominalism and what he calls dynamic nominalism. Strict nominalism holds that objects have nothing in common except our names for them. The key assumption here is that names, more in the sense of categories, are given by human beings rather than by nature and that these categories are essentially fixed throughout time (Hacking 2007). On the other hand, Hacking, with what he calls dynamic nominalism, posits that many categories come from nature, not from the human mind, and these categories are not static (Hacking 2007). He gives examples of horses and planets. Horses cannot be said to have nothing more in common than the category of horse that they occupy. They have characteristics, that are naturally present, that unify them as beings (Hacking 2007). This was not something that came from our own minds. Planets also have naturally present characteristics that unify them.

However, the category of planets has changed over time (Hacking 2007). Our understanding of what can be considered a planet and how we have organized our solar system accordingly has evolved.

In the case of experience, dynamic nominalism claims that it is not that different kinds of people are becoming increasingly recognized. Rather, a kind of person comes into being at the same time as the kind itself was being invented (Hacking 2007). Hacking speaks of people and their experiences in this way using the example of multiple personalities. He claims that multiple personalities as an idea and as a clinical phenomenon was invented around 1875. Prior to that there may have been cases that presented with symptoms that would later be classified under multiple personality but this categorical distinction was not understood as a way of being in the world (Hacking 2007). After 1875, there were an increasing number of cases. This indicates precisely that our categories and the people within them "...conspire to emerge hand in hand, each egging the other on" (Hacking 2007, p.165). It in this same way, autism as an idea and as a clinical phenomenon was invented, one could claim in 1943, in concert with the emergence of the people in this category by way of diagnosis.

Beyond being a theoretical approach to understanding human experience, the concept of 'making up' people has a practical facet. 'Making up' people is not only a mode of description but it also opens up possibilities of action, possibilities of ways to live. Hacking argues that "if a description is not there, then the intentional actions under that description cannot be there either" (Hacking 2007, p.166). But he clarifies that his point is not one of impossibility. He is not orienting the individual in terms of the limits of the ways it is possible to exist in the world. Rather he is arguing that the space of potential ways to be in the world that surround an

individual would be fundamentally different if certain modes of description were not available (Hacking 2007). "Hence if new modes of description come into being, new possibilities for action come into being in consequence" (Hacking 2007, p.166).[9]

This is precisely the effect that autism, as a biomedical categorical distinction of experience, is having at the Joy Centre and its surrounding communities. Although there is a rich Ethiopian history in which the behaviours now falling under autism, and likely many others under various psychological and developmental diagnoses, were primarily interpreted in spiritual terms, I observed a consequential shift from this. Instead, making up and understanding 'autism's child' has and continues to open up new possibilities of action and ways to live, particularly by way of the Joy Centre's establishment. Not knowing what was 'wrong' with their child is the most difficult part according to many parents. Burdened by a lack of medical, and oftentimes financial resources, most parents described a difficult journey of trial and error to understand what they can do for their child. Compounded with this, parents expressed feelings of shame and self-doubt when they did not know why their child was this way. Questions of, "What could I have done?" or "What can I do?" can seem to have limited and yet limitless answers.

But once parents knew the 'problem' was autism, though most described initially feeling discouraged, they were comforted by the fact that there were steps they could take to help their child. Considering Ruth's experience (first section), her framing of autism as the tier of her son's mouth did not mean, in her eyes, that her son would never speak again, especially since, to the best of her judgement, her son was born normal. A few other mothers eventually expressed

[9] There is also a question of power to consider. Hacking mentions that making up people is intimately linked to control (Hacking 2007). It should be noted who creates these categories and what purpose they serve in a social or political sense. While Zemi did not create the category of autism, it would be another avenue of analysis to deconstruct the subject position she occupies.

similar ideas. They saw a potential end to their struggles, caring for a child with autism. They saw their children's behaviours as problematic with the potential to be resolved. One woman told me, "[When I bring my son h]ere, I don't think of him as going to school. *Le hikimina new yemetaw* [lit. He is here for treatment]." Even though the time her son spends at the Joy Centre appears to be educational in form (e.g. schedule is 9 am to 3 pm from Monday to Friday, he goes to class and has a teacher…), this mother holds it to be a certain kind of medical treatment and care. This may be in part attributable to the medical language adopted by the Joy Centre when speaking about autism. There was talk of *treating* autism with a variety of sensory and behavioural therapy programs. A certain kind of temporality is being implied. By referring to treatment instead of education, this parent is communicating an expected end date after which point she is hoping that her son will return to his 'normal' self. Many mothers confided in me their hope for their children: that they would go to 'normal' school and lead a normal life. Positing in a way that this time at the Joy Centre is an intermediary stage, parents were hesitantly hopeful that someday, somehow, their children may be able to leave autism behind.

None of these possibilities of action, whether conceived of as education or treatment, could exist without 'autism's child'. Parents may not accept the biomedical temporal characterization of autism (that it is a lifelong disorder) in their child's case, but what is more pertinent is that parents are developing some understanding of autism that then opens up possibilities for the ways they can care for their child. Parents were also introduced to hopeful possibilities through the experiences of improvement and success of their fellow community members, but primarily by Zemi's story of success with her son, Jojo.

Conclusion

I argue that the child's lack of or regression in verbal ability, which Ethiopian parents spoke of in terms of the untying of the mouth, is emblematic of pathology for these parents, particularly as it is the primary descriptor of 'autism's child'. Considering historically religious interpretations of possession and a tide mouth, parents' resistance to accept the biomedical conceptualization of autism while bringing their children to the Joy Center seeking care for this very condition points to the integrative work they are doing to formulate their own understandings of autism. As they do this work, parents are negotiating, in a sense ' making up', who and what counts as 'autism's child'.

Chapter 2. "*Aysemam*" [lit. he does not listen]

Listening and Not Listening: Expectations of Obedience for 'Autism's Child'

Leading up to and upon my arrival in Addis Ababa, I did not know how knowledge of autism would be situated. Obviously since the Joy Centre was a school for children with autism, there were at least a few people who were familiar with autism as some kind of a diagnostic category. However, I was unsure of the extent to which autism was understood as a biomedical concept, within the Centre as well as extending into the local community. Was autism a term that was part of the layman's language in Ethiopia? Or was it recognizable only to those with some specialized knowledge? These questions were answered in part on my commute for my very first day at the Joy Centre. It had only been a few days since I had arrived in Addis Ababa and I was still buzzing with energy as a result of all the changes I was experiencing. That morning, my aunt had warned me of the intense rush hour traffic in the city so I had decided to take a contract taxi[10] for my first day since I had yet to learn how to efficiently move about the city. As I settled into my taxi for my commute, the driver introduced himself and soon the conversation turned to the purpose of my trip to the Joy Centre. While the conversation included interspersed niceties about my family and background, for the most part the driver was very curious about autism. He recognized the term and had even heard of the Joy Centre, "That's the one founded by that lady. I've heard her talking on the radio and tv about the school and the kids that go there." He was particularly curious, not necessarily about autism itself but, about the children. He asked questions pertaining to the experience of autism. He asked questions like, "Is it that these

[10] Contract taxis are identical to taxi services here in Canada. While it is a readily available means of transportation, more commonly people commute using regular taxis, which are minivans that function similarly to buses here.

children are not able to talk or that they don't talk? Is it a matter of *aff meftat*?" He also asked, "These children, *yisemalu* (lit. do they listen)? *Mesmat yichilalu* (lit. can they listen)?" Evidently, his first questions pointed to one of the key elements, I later found out, that formed parents' understanding of autism (as per Chapter 1). Now, I gesture to his second set of questions that, similarly to the first, I later found also highlighted a central aspect of parents' understanding of autism.

In this chapter, I develop listening and not listening as a part of my conceptual framework for the way parents know and care for autism. Parents and teachers at the Joy Centre asked me, as well as one another a set of questions in reference to these children: '*Yisemal*? *Tisemalech*? *Mesmat yichilal*? *Mesmat tichilalech*?' Literally translated, these questions become 'Does he listen? Does she listen? Can he listen? Can she listen?' The word listening itself refers to more than the physical sense of hearing. Beyond the aspect of sensory capture, parents' expectations of listening includes the expectation of an appropriate behavioural response from their children when they are asked to do something. This pairing is significant because, for parents, it is embedded with a deeper social meaning that reaffirms their relationship to their child. Obedience means respect and a mutual understanding of the relationship. When a child listens, he or she is embodying respect and the knowledge that they ought to to obey their parents. Based on these parents' experiences, I argue that listening is the frame through which Ethiopian parents understand obedience as a given element in their relationship with their child. I explore how parents have developed an understanding that they cannot expect obedience from their child (autism's child) the way they might expect it from a 'normal' child. What does it look like when a child does *not listen*? What does this say about parents' expectations of listening? How do they

cope when their child does not listen? How are they developing different expectations for their children (if they are) since they cannot expect obedience? How do they cope with these shifting expectations?

What is listening?

As we approached the Joy Centre on that first day, the driver explained why he was so curious.

The reason I am asking you so many questions is that there's a girl I know, the daughter of my friend. She's 2 years old and *gena aff alfetachim* (lit. she has not untied her mouth yet). But she's very good and *tisemalech* (lit. she listens).

This description on its own did not necessarily convey much about autism but it was my first encounter with what would end up being a distinguishing behaviour.

The ability to listen in itself denotes an underlying cognitive and social skill. Beyond the physical ability to hear, listening requires the cognitive skill of attending to the person speaking to you and understanding what is being said, as well as the social skill of responding appropriately in that context. Both these cognitive and social skills are measurements used in diagnosing autism, in that children with autism generally lack these to some extent (Bailey & Rutter 1991; Ashburner et al. 2014) . At the Joy Centre, rather than describing cognitive or social ability, many parents would often refer to their child's ability to listen, describing this ability to listen (or rather not listening) as one of 'autism's behaviours'. Teachers would also refer to a child's ability to listen as part of an assessment of the child's general capabilities. Listening indicated a higher level of capability or functioning and was a way to differentiate children who

could participate in certain activities. For example, once a week, a few teachers would take some of the older students for a walk around the neighborhood. The students whom were chosen to go on this walk were chosen partly on their physical capabilities (e.g. will not get tired too quickly) and partly on their ability to listen. This was to ensure the student's safety (e.g. would cross the street when told to, would wait if they walked too far ahead).

An aspect that is particularly significant in the case of this marker is that children with autism are able to learn to listen. In the Euro-American framing of autism, intensive intervention strategies based on learned behavioural principles are actually highly recommended by medical professionals and are often applied from the point of diagnosis (usually between ages 2 to 3) onward (Bailey & Rutter 1991; Ashburner et al. 2014). Essentially, desired behaviours (e.g. responding appropriately to specific demands) are paired with positive reinforcement until those behaviours are learned. The Joy Centre models itself after this framing of autism and so aims to apply these strategies to encourage improvement in the children's behaviours. It is within this model that listening or not listening functions as a marker of autism for teachers and that parents are taught to cope with their children who do not listen.

Not Listening to the Parent

In this section, I look to what and how parents described the problem of listening in their children with autism. Over the course of my time at the Joy Centre, I had come to know a few mothers particularly well and Mariam was one of these mothers. By the time she and I sat down and talked about her experiences, I had volunteered in her son's class and so I was aware of the behaviours she would refer to in the stories she told me. Listening, or more notably not listening,

is a difference she noted in her son from a very young age, closely following a 'tied mouth'.

"The main difference that I noticed was that he got quiet. His mouth was not untied. But then I also noticed that not only was he quiet but he also seems to not listen. When I ask him to do something he doesn't do it. Or other times he does the opposite of what I say. Or other times he just screams and yells and hits because things don't go his way. It's hard to manage."

When Mariam referred to her son's inability to listen, I knew from my experience with her that she was not referring to her son's physical capability of hearing. Rather, she felt there was something off in the way that she could not get a proper response from her child, particularly when she asked a specific task of him. This is where in many of my conversations with parents, as well as teachers, it became clear that it was obedience, presented as listening, that was of underlying importance.

In my conversations with parents, I found that they did not speak outrightly about disobedience or their frustrations with discipline. Instead, the word listening took the place of obedience. This is in part because of what listening encompasses in Amharic. As in English, the literal sense of the word listening in Amharic refers to attention to and acting on what someone has said.[11] However, in the context of a parent-child relationship, though listening appears to be the same in practice, it carries another moral layer of meaning.

Alem, another one of the mothers at the Joy Centre I grew close to, explained to me what was most difficult about having a child that does not listen. She felt that when dealing with

[11] One could also not act in response to what someone has said and still have heard the person, but my point about listening focuses on what parents understand and experience not listening to be (wherein a lack of action is considered an inappropriate response).

routine occurrences within her home, such as asking her son to pick up his toys or to stop doing something, her son's not listening did not seem like a significant problem. Instead, it was a frustrating continuous chore, requiring that she be patient with and pay particular attention to her son. At other times, especially out in the community, her son's inability to listen was deeply hurtful.

"There was one time, me and my son were out. We were waiting for a taxi and there were lots of people around. My son was standing beside me. This man who was begging for money came up to us and asked me for money. I politely said no and the man walked on. I guess when I wasn't looking my son must have touched him or something because he came back and started yelling at me. He was yelling, saying, 'You should discipline your son! Don't you teach him discipline?! He can't simply touch strangers! It's not proper! What kind of mother are you?!' You see, I knew this man was going too far [by yelling] because I didn't give him any money when he asked. So I didn't respond to him because I didn't want to make the situation worse. But then he started yelling at my son. I became angry and embarrassed because people were looking now. The man knew, he could see that my son wasn't normal if he looked at him better. But he didn't want to, he wanted to yell. Thankfully, other people defended me and my son from this man and made him leave us alone. They knew my son didn't know better. But that was a rare situation. People are not always understanding, they don't always realize that something else is going on. Mostly, they blame me. **As a mother, my child should listen to me.**"

At the end of her story, this mother says why her child's inability to listen is a problem: her

expectation is that her child should listen to her because she is his mother. She presents this expectation as being imposed upon her by others (which may be in part true) however, as we spoke further, she reiterated this expectation as one she held for herself. Further, she explained to me that her experiences prior to this moment have shown her that she cannot expect that her son won't touch someone because she told him not to. In an experience that other parents also shared, whether their child will listen to them is unpredictable. They cannot expect it. In other words, obedience (in the sense that it is compliance or listening to what is being asked in recognition of another's authority -- "*as a mother, my child should listen to me"*) is what is being expected from parents, of children. And in the case of 'autism's child', this expectation does not stand.

In reference to this mother's sense of an externally imposed expectation that she discipline her child, this reflects fundamental moral and religious undertones in Ethiopian society. Parental expectations of obedience are a part of the larger work of caring for and rearing children.

Caring for and Child-rearing

In the process of developing this project, I deliberately chose to focus on the way parents *care for* their children with autism. With the Joy Centre only having been founded a little over fifteen years ago, I was aware that doing this work would position me at the crux of a process of introduction: the Joy Centre is a site where specific epistemological and clinical practices were bringing "autism" into being in a specific form for the first time. While formal services and institutions of care for autism may be relatively new to Ethiopia, it would be wrong to assume that Ethiopian parents previously had no way to care for their affected children. I argue instead

that existing ways of caring for these children are undergoing a transformation. With the recognition of certain behaviours as *symptoms* of a condition, the work of caring for those behaviours are modified.

I purposefully use "caring for" as a concept, rather than breaking down the concept of care itself, because my intent is to focus on the relations between children understood to be autistic, and their parents and practices of care that occur in that space. Drawing on Mol's framing of such practices of care as an open-ended process, without clear boundaries (see Introduction), I use the term caring for to refer to the collaboration of various hands working together. Such systems of care (usually among family, community, and church) are likely so embedded in the routines of the everyday that they are normalized, to the extent of potentially being rendered invisible. This kind of work that is often understood in a material sense, physically working, lifting or supporting to care for the other. (Wilkinson and Kleinman 2016, 162). In Amharic, this translates as *masadeg* [lit. to raise] or *menkebakeb* [lit. to pamper]. The literal sense of these words gesture to the physical work (the specifics acts, such as bathing or feeding) of caring for someone. Beyond this, however, in the case of a parent and their child, caring can refer to a sense of responsibility or obligation to teach discipline and values. This gestures to the the emotional labour of caring for someone, which in Amharic can be translated to *maseb* [lit. to think] or *metchenek* [lit. to worry]. This sense of caring refers to the inner emotional labour of caring for someone. For example, in the case of a mother caring for her son, to say *silesu tasibalech* or *titchenekaletch* [lit. she thinks about or worries about him] is meant to communicate a kind of constant care that is passing from mother to son in the form of emotional labour. In my work, when I refer to how parents care for their children, I am looking at what

parents understand their child's needs or issues to be and how they choose to address or look after them.

In analyzing the nuances in the ways that Ethiopian parents care for their children, this kind of care-work, within this relational context, is a significant part of what parents understand to be their responsibility or obligation in rearing their children. For the parents at the Joy Centre, both the physical and emotional labour of caring for their children in particular ways, because these children have particular needs, shape the way they are rearing their children. As they develop their understanding of autism as a biomedical category, parents are reframing and reinterpreting their children's behaviours and are adjusting their expectations for their children accordingly. A child who does not pick up his toys when told to is no longer understood as a disobedient child and therefore is no longer punished as such. Instead, the child is known as not understanding the appropriate response to the instruction which they were given and is then taught the appropriate response.

As I mentioned above, "care" can be translated in Amharic as *masadeg* [lit. to raise], referring to more than the physical work of caring for someone. Again, in the case of a parent caring for their child, a specific form of this care is the teaching of closely-held values. In this sense, with listening understood as obedience, a child's lack of listening can be felt as inadequacy on the part of the parent or the child. For the parents I spoke with at the Joy Centre, they experienced this as an ineffectiveness or failure in their child rearing practices.

Anthropologist Naomi Quinn presents a theoretical framework for the analysis of child rearing practices in different cultural contexts, from the perspective that select universal elements exist within differing cultural child rearing models. Drawing on the concept of culture as shared

cognitive schemas that arise out of shared experience rather than as something monolithic and unchanging, Quinn examines early child-rearing experiences that are often expected to have lifelong influence on the resulting self (2005, 478). Moving away from culture and personality theorists in psychology that focused on isolated traits such as swaddling, or the timing and severity of certain practices such as toilet training, she argues that the more global features of value-laden child-rearing doctrines and deliberately engineered rearing strategies are responsible for inculcating these values (Quinn 2005, 478).

In psychological anthropology, cultural models are cognitive schemas that members of some group or class of people share. They are learned through experience as are other cognitive schemas, with the exception that these experiences, and the cognitive schemas that result from them, are widespread in a group (Quinn 2005, 479). In child rearing, a cultural model specifies the kind of adult that child rearers desire to raise, along with a set of practices (e.g. certain forms of punishment, assigned roles in the home) thought to most effectively raise a child to be such an adult, the result being the production of the kind of adults valued in that community (Quinn 2005, 479). Sometimes the responsibility of child rearing is understood as a reductive form care-taking, limited only physical work to fulfill the child's basic needs (e.g. dressing, feeding, bathing); sometimes it is instruction in knowledge that may be viewed as practical in nature and having little direct relationship to values (Quinn 2005, 479). However, cultural values about the kind of individual parents strive to raise can be embedded into routine care-taking, instruction in practical knowledge, and the management of children's security and development (Quinn 2005, 479).

In her theoretical analysis of the universals of child-rearing, Quinn presents four central features which she argues form the variations of child-rearing models. Of these four features (constancy, emotional arousal, approval or disapproval, and emotional predisposition), I draw on the two most relevant to the experiences of parents at the Joy Centre.

Emotional arousal -- by various widespread techniques such as beating, frightening, teasing, shaming, or praising -- greatly heightens the effect of the kinds of messages that parents communicate to their children, making the experience accompanied by arousal especially memorable over the long term (Quinn 2005, 481). The use of emotional arousal in the way parents teach their children lessons and impart values are tied to evaluations of the child as approved or disapproved (Quinn 2005, 481). Quinn argues that approval and disapproval are intrinsically emotionally arousing because of their implications of care. She suggests that a caretaker's love and approval are reassurances to the infant that attachment to the caretaker is secure and the infant is safe; love withdrawal and disapproval arouse insecurity, signaling the possibility of neglect or even abandonment (Quinn 2005, 482).

I found that in my work, Ethiopian parents' expectations of obedience are a function of these two features. Though it may vary within different cultural contexts, according to Quinn, models for rearing children to be valued adults are everywhere invested with 'moral direction' or 'moral rectitude'(Quinn 2005, 490). The moral dimension to beliefs and practices surrounding child rearing is evident, given that this task engages adults in the active consideration and reproduction of their dearest-held values (Quinn 2005, 490). Given that almost all the parents at the Joy Centre (and generally in Ethiopia) are attached to some religious group (the dominant three being Orthodox Christian, Pentecostal Christian, and Muslim), it would be imprudent not

consider the shaping influence of these beliefs on parents' expectations. So not only is the parent's expectation of obedience from their child meant to be reflective of a mutual understanding of the parent-child relationship, but it also demonstrates a reproduction of religious values (one ought to obey their parents).[12] In the case of autism, a challenge arises when these values are not being understood by the child.

However, in these cases, Ethiopian parents understand that listening, or obeying, is something these kids struggle with. Rather than a defiance against authority, parents explain their children's seemingly disobedient behaviour as a lack of knowing that what they are doing is wrong. Theoretically, understanding that this lack of knowing is a character of *autism's child* allows parents to reframe how they discipline their children. A child's behaviour is no longer anyone's fault and so can be dealt with differently. In practice however, this is a difficult task. Miriam told me of an incident with her son that depicts the gap between knowing and caring for one's child as *autism's child*.

"My son was playing with his ball in our living room one day. He was quiet but at one point he started throwing the ball around. I told him again and again, don't throw the ball. You're going to break something. But he doesn't listen, he kept throwing the ball. When he threw the ball he hit the glass cups on the table. The cups broke and there was glass everywhere. I yelled at him, saying 'I told you not to throw the ball! This is why! You have to listen!'. But this only made it worse. Then he started screaming and crying. I know he didn't mean to break it. And I know, I shouldn't have yelled at him. He doesn't know. He doesn't

[12] Notably, I have chosen not to delve into the specifics of what these religious values are because when parents were speaking with me about obedience, it was through the frame of listening and they did not directly reference their religious beliefs. However, over the course of our conversations, they communicated (by speaking of their situations as God's or Allah's will and their commitment to going to church or praying) that who they are as religious individuals filters the way in which they care for their child.

understand. I just lost my patience. It's hard."

When this happens, when their children do not listen (and therefore do not obey), parents explained to me that they know their child may not be purposefully disobeying them and that this is a problem that they attribute to autism, a manifestation of autism's influence. Though one may interpret her son as being at fault for disobeying his mother, Miriam expressed disappointment in herself.

Over the many instances we spoke, Miriam always acknowledged that her son's behaviours were in some sense a product of his condition. Knowing this, however, does not do away with the challenge of reframing how one can rear a child with autism. Teaching a child with autism to listen and creating alternate means of discipline is work that requires an understanding of how exactly a child with autism is impaired in those ways. In order to cope, parents are learning new strategies of caring for their children without expecting obedience from the children's teachers. These strategies are a way of teaching listening, rooted in behavioural principles and hence part of the biomedical framing of autism presented and promoted by the Joy Centre.

Not Listening to the Teacher

In this section, I look to what and how teachers described the problem of listening, considering their employment and training at the Joy Centre. In autism, severe abnormalities in social behaviour coexist with aberrant attention and deficient language. In the attentional domain, attention to people and socially relevant stimuli is impaired the most (Ceponiene et al., 2003, 5567). One of the components of the social communication deficits in autism is peculiar

attentional behaviour. Individuals with autism show attentional preference to objects over people and a lack of a drive to communicate (Ceponiene et al., 2003, 5567). The neurofunctional deficits underlying this pattern of behaviour are not yet understood, although recent research revealed disorders in many aspects of attentional behaviour in autism. They include abnormalities in spontaneous looking, focused attention, and voluntary shifting of attention (Ceponiene et al., 2003, 5567).

It has been suggested that individuals with autism might have difficulty in encoding and representing sensory features of physically complex (but not simple) stimuli (Ceponiene et al., 2003, 5567). Such a deficit would place autistic individuals at a disadvantage in processing signals of social communication (e.g. facial expressions or speech) because of their multifaceted and rapidly changing nature. If severe, such an impairment might severely compromise the extraction of the meaning from the ongoing stream of social information (Ceponiene et al., 2003, 5567). Furthermore, if social stimuli are not particularly meaningful to individuals with autism, they might develop no motivation to attend to this type of information or, worse, they might even develop resentment to the stimuli and situations to which they feel they should but cannot relate (Ceponiene et al., 2003, 5567).

In Miriam's case, a feeling of resentment arises from not being able to reprimand her son in a way he would understand, leading to his response of crying and screaming. Further, Miriam's response to her son's behaviour may itself contribute to demoralizing her son from learning the appropriate responses to her instruction. As such, the teachers at the Joy Centre play a pivotal role in the parents' care for their children. Miriam explained to me that on many occasions, when she encountered incidents with her son like the one described above, she would

consult her son's teachers for the appropriate disciplinary strategies. "The teachers here, they told me it's better not to yell at him. He doesn't know. They tell us it's best to talk calmly and explain to the child what we're asking, to show the child." There is a specific kind of work that needs to be done in order for a parent to have their child with autism listen to, or in another sense obey, them. This work deviates from simply instilling a basic sense of respect and recognition of authority in their child, as is the norm in child rearing practices.

The teachers at the Joy Centre hold a unique position in the way they care for these children. While they all had close relationships with the children, some even saying they felt these children were like their own, they work with a certain understanding of autism as a condition that can be mediated through the use of behavioral principles. Establishing a routine and ensuring that the child follows it, as well as rewarding or praising the child's appropriate behaviours, and redirecting the child's inappropriate ones, are essential to helping a child with autism 'improve'. Their training in the care and education of children with autism affords them specific strategies for managing and decreasing problem behaviours (e.g. biting, hitting) and teaching desired behaviours, the primary one being listening. The teachers apply these techniques consistently as part of each student's uniquely designed behavioural and educational programs. However, in order for these programs to be most effective, the same behavioural techniques need to be applied within the family context in the home.

While describing the way the teachers work with the students at school, Miriam noted, "They know the children better you know. The teachers spend so much time with them, they know how to handle them better. They know how to get them to listen and the children listen to them better." She went on to tell me how just last week, her son's teachers were telling her that

her son had refused to partake in the classroom cleanup at the end of the day. Each of the teachers tried repeatedly asking him and coaxing him into joining the other students, helping them clean up the classroom as they usually do. He refused and exhibited problem behaviours (e.g. banging the table, kicking, screaming, biting his hand, etc.) That is, until Ellen, one of the head teachers, walked into the classroom. With just one look from Ellen, her son got up and started putting his supplies basket away. "I'm so glad he listens like that at school. It means he's improving. I would be so happy if he listened like that at home."

Certain child rearing practices (e.g. punishment for misbehaviour) may not be as effective in relaying the importance of certain values from parent to child. Particularly in the case of the children at the Joy Centre, it was the parent members of the child's rearing community that were primarily struggling. The teachers, due to their training and experience, were better able to implement practices that could more effective teach important lessons, such as obedience. This causes a shift of weight in the child's rearing community, with teachers taking on a more primary role and leaving parents to follow their lead. Although this shift occurs, in an adaptive sense, for the benefit of the child, tensions can and do emerge. A clear distinction is sometimes created between a child's home life and school life, wherein the child's behaviour is dependent on their environment, proving to be an additional challenge for parents.

For parents, as they come to develop their understanding of autism, 'not listening' is a characteristic of their child as 'autism's child'. They work to develop ways to care for their child despite the fact that their expectations of obedience are not met. Part of this work includes following the lead of the teachers and trying to model the 'correct' ways to teach listening, but as illustrated by their stories, they continuously struggle with trying to teach and care for their

children the 'right' way. Significantly, in each instance that a parent had to deal with their child not listening—particularly ones where the parent is not successful in following through on behavioural principles—they confront themselves, and not their child. They know their expectation of obedience from their child does not hold, and so instead they develop different expectations for themselves, ones where instead of reprimanding or punishing, they work to teach their child to listen.

Mothering Autism's Child

Though I have spoken predominantly in terms of parents, the great majority of the parents involved at the Joy Centre were in fact mothers. Further, all of the teachers were women. The intersection of this marker of listening and the dominant presence of mothers and mother figures is significant. When considering who the disciplinarian is, according to traditional gender roles in the family, one might expect it to be the father. However, in the case of autism's child, the combination of particular needs and alternative disciplinary strategies (with an eye to many other factors that impact the family unit) places mothers in this role.

Mothers of children with autism sometimes encounter strangers who blame them for their children's misbehaviour rather than attribute the behaviour to the child's disability (You & McGraw 2011, 582). It can be quite difficult for a parent of a child with autism to have patience during problematic interactions with strangers. Public outings can be complicated because of the discrepancy between a child's appearance and that child's behaviour. Strangers do not immediately understand that the child may be behaving inappropriately because of a specific condition or disability. This discrepancy brings about situations in which the parent has to decide

whether to share their child's diagnosis or maintain their own and their child's privacy (You & McGraw 2011, 587). In particularly stressful circumstances, parents may feel they do not have a choice but to divulge their private situation in order to defend themselves against negative interactions with strangers. Miriam explained that even this can be to no avail.

"Another time, my son and I were in a taxi. He was playing a game on his tablet. He was getting a little hyper so he was starting to yell a little. I tried to tell him to quiet down because there were other people around but he wouldn't listen. A few of the other people started saying to me, 'Aren't you going to tell your son to be quiet? Doesn't he listen?' So I tried to tell him again but he wouldn't listen. You know how these kids can be when they get hyper, they are loud. And it's very difficult to get them to listen. I became embarrassed when people kept saying, 'Doesn't he listen?' I tried to explain that my son has a problem. After a little time, everyone around us was getting more frustrated and I was getting more embarrassed. So they made us get off the taxi."

It is evident that caring for a child with autism can be a struggle with negative attitudes towards disobedient children present in society. These prejudices can be extremely difficult to work against. However, parents who move beyond a focus solely on their own child to a focus on the larger community of individuals with similar conditions or disabilities showed resilience in their efforts to adapt to having a child with autism (You & McGraw 2011, 588).

In 2011, Hyun-Kyung You and Lori McGraw conducted research with mothers of children with autism in South Korea. They aimed to understand how mothers make sense of themselves as well as how they understand themselves and their children with autism in relation

to broadly available sociocultural ideals about gender and disability, based on the idea that both cultural and material practices shape mothers' understandings of themselves and their relationships (You & McGraw 2011, 583). This approach reflects their argument that people construct their worlds and themselves through the creation of symbolic and representational stories or narratives (You & McGraw 2011, 583). You and McGraw found that individuals with disabilities are stigmatized in Korea, partly because they are viewed as people who threaten reciprocal family ties. They write that Koreans believe that having a disability inhibits an individual's ability to care for aging parents, and to pay respect to ancestors (You & McGraw 2011, 580). Relatedly, they suggest that individuals with disabilities also are less valued in Korean society because they bring shame to their families by not conforming to societal ideals of success and by threatening the homogeneity of society (You & McGraw 2001, 581).

Mothers who have children with special needs can feel overwhelmed by their responsibilities. Their responsibilities reach beyond simply raising their children. You and McGraw found that these mothers work to compensate for their child's special needs in order to still raise and produce individuals that are visible and valuable in society. After an initial focus on "curing" their children, Korean mothers began to redirect their energy to learning more about autism and on teaching their children social and communication skills (2011, 590). They emphasized that they wanted their children to become happy, independent adults (2011, 590).

One key to this transformation, according to the stories women told, was the support that they received from similarly situated mothers (You & McGraw 2011, 590). Of course, it has been long known that social support helps mothers of children with disabilities cope with stress (You & McGraw 2011). You and McGraw argue that parents who move beyond a focus solely

on their own child to a focus on the larger community of individuals with similar conditions or disabilities showed resilience in their efforts to adapt to having a child with autism (2011, 588).The mothers that they spoke with explained that in South Korea, a mother's success is equal to her child's success (You & McGraw 2011, 591). For example, when a child receives high marks, goes to a prestigious university, and finds a lucrative job, these Korean women believed that this success results from good mothering (You & McGraw 2011, 591). At the Joy Centre, Zemi's story of "success" with her son has become a source of comfort and the epitome of what it means to be a good mother of a child with autism. These success stories became the standard of care and child rearing to which mothers held themselves. While many mothers spoke of Zemi as a motivating and inspiring figure, helping them to push through the difficulties of caring for a child with autism, few acknowledged that the "success" of a child with autism depends on many factors out of one's control, such as the severity of symptoms and available resources.

Conclusion

In this chapter I have attempted to explain how listening is the frame through which Ethiopian parents understand obedience as a given element in their relationship with their child and the ways in which they see autism as interfering with this element. I have shown how parents have developed an understanding that they cannot expect obedience from their child (autism's child) the way they might expect it from a 'normal' child. Particularly significant is the duality of listening, as the lack of listening appears to have a different kind of importance between teachers at the Joy Centre and parents. A child's inability to listen to his or her teacher appears as a social problem to be addressed with various behavioural strategies. However, when the child does not

listen to his or her parent, the effect goes beyond (or perhaps overlaps with) a social problem. It becomes moral and relational, bringing up the question of what it means to be a good parent (namely mother).

Chapter 3. "*Terebishwal"* [lit. he is disturbed]

Inner Disturbance as Socialized Sensibility in Autism's Child

It was early on in my days at the Joy Centre that I had met Alem, one of the mothers who spoke very openly with me about her experiences over the course of my stay. As I was coming into the Centre's courtyard one morning, she stopped me on her way out asking if I was one of the teachers. Explaining that I was one of the newer teacher's assistants, she asked me to please check on her son. "Lately, he has been doing okay. He was fine this morning. He got ready as usual and he was even okay on our way here. But, *terebishwal izeeseeders* [lit. he became disturbed when he got here]." She was worried because her son was yelling and making repetitive sounds, stomping his foot on the ground and aggressively rocking back and forth, biting his one hand and banging the other on a table or against his head. These behaviours were indicative to her that something was bothering her son but she did not know what it could be. As we are speaking, another member of the staff joined us and Alem relayed her concerns to them, saying of her son "*Terebishwal zare* [lit. he is disturbed today]". They reassured her that her son will be looked after because the teachers know what to expect and sent her off telling her she need not worry.

It is not uncommon to hear parents in Ethiopia describe their children as *rebash*, at least from time to time. This Amharic word is used to describe children who engage in behaviours with a kind of restless, troublemaking quality, behaviours such as fighting with other children, breaking objects or, more generally, disobeying what they are told. Alem's description of her son's state, however, repositions this sense of restlessness within the child. To say of someone

terebishwal in Amharic is to describe that person as lacking calm and stability within him- or herself and is instead experiencing some kind of agitation, an inner tension perhaps escalating to the point of anger. Notably, although an individual in such a state may behave in particular ways, this description points to that individual's inner experience.

In this chapter, I argue that the way parents refer to an 'inner disturbance' within the child is significant because it suggests that parents understand these children are capable of being deeply emotional, even if they (both the parent and the child) cannot make sense of it. Parents did describe their child's particularities in terms of sensitivity to light, sound, etc. However, in instances of what looks like a meltdown or what is described in autism literature as a sensory overload, parents attribute more meaning and depth to what their child has understood and the reasons why their child is upset.

The 'problem' of sensory processing and moral distinctions

One common description of individuals with autism is that they experience sensory processing problems and, in these individuals, sensory overload is represented by behavioural responses (Myles, Dunn, Rinner, Hagiwara, Reese, Huggins & Becker, 2004, 288). A lot of the behaviours parents described when their child was experiencing these inner disturbances can be categorized as self-stimulating behaviours, which would be interpreted as a behavioural response to a sensory overload. The stimulation can be auditory (e.g. making repetitive noises, listening to a video on high volume), visual (e.g. looking at a picture by holding it right up to their face) or physical (e.g. rocking, hitting themselves). Psychological theories suggest that children with autism engage in these behaviours as an atypical sensory response to their environment. This

response is driven by a hyper- or hypo-reactivity to different sensory input (Ashburner et al. 2014, 30). For example, a child engaging in self-stimulating behaviours would be doing so because they are needing high levels of stimulation. However, that same child may find the ambient noise of a busy street to be overstimulating, also referred to as a sensory overload. In these situations of overstimulation, children with autism often engage in self-stimulating behaviours as a reaction to the sensory overload.

Autistic impairments are formally organized into a triad of symptoms used in the diagnosis of autism, including Asperger's syndrome. This triad includes: specific abnormalities of social behavior, particularly those affecting reciprocal relating and empathy; communication difficulties affecting non-verbal conversational skills; and lack of creativity and imagination, accompanied by a characteristic rigidity and repetitiveness of behavior (Kennett 2002). All three categories of impairments are relevant to one's capacity to receive and respond to the sentiments of others, which are in turn commonly linked to the autistic person's ability to make moral distinctions, and moral motivation.

In the DSM-V, a section of the diagnostic criteria for Autism Spectrum Disorder details behaviours and severity in the deficit of social communication. Categories of deficits include social-emotional reciprocity, nonverbal communicative behaviors used for social interaction, and developing, maintaining, and understanding relationships. Severity, the manual specifies, "is based on social communication impairments and restricted repetitive patterns of behavior," of which "hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smell" is one. (Autism Spectrum Disorder 299.00 (F84.0); APA, 2013)

Autism is a spectrum diagnosis, meaning it includes the full range of severity under a single label. Severity as the frame through which self-stimulating behaviours are interpreted has significant ramifications. The Joy Centre is a non-governmental organization that is organized on the basis of need: the financial need of the parents, and the need for care based on the severity of the child's condition. Not every child at the centre has been formally diagnosed, and this is not a requirement for admission. Specific members of the staff are trained to use an assessment tool to evaluate the children that are not already diagnosed. This is done, as is also true in standard biomedical clinical situation, through a subjective assessment (conducted by specifically trained teachers) about what amount or intensity of specified behaviours can be considered mild, moderate or severe. Because there's limited space and a long waiting list at the Joy Centre, mostly children with severe symptoms are admitted. I was told by teachers at the centre that parents who have children with mild to moderate symptoms may not even seek out additional professional help or come to the centre, especially if their child is able to attend school. The measurement of severity, and its use in triaging students for spots at the centre, speak to the fact of limited resources.

The interpretation of behaviours as deficits or impairment in sensory processing is part and parcel of the conceptualization of autistic 'aloneness'. Lack of interest in affective contact with others is often how autism is characterized, particularly as it appears very early in life, and this presents a striking contrast to the affective behavior of most children at a young age (Kennett 2002). This ties into the most general description of social impairment in autism as a lack of empathy. A much-cited characterization by Uta Frith reads:

The most general description of social impairment in autism is lack of empathy. Autistic people are noted for their indifference to other people's distress, their inability to offer comfort, even to receive comfort themselves. What empathy requires is the ability to know what the other person thinks or feels despite the fact that it is different from one's own mental state at the time. In empathy one shares emotional reactions to the other person's different state of mind. Empathy presupposes, amongst other things, a recognition of different mental states. It also presupposes that one goes beyond the recognition of difference to adopt the other person's frame of mind with all the consequences of emotional reactions. Even able autistic people seem to have great difficulty in achieving empathy in this sense (quoted in Kennett 2002, 346-347).

Difficulty in achieving empathy bears on understandings of an individual's personhood. Empathetic understanding of others is viewed in psychology as the foundation for developing a moral concern for one's actions towards others, as well as a general moral consciousness (Kennett 2002, 349). One's understanding of right and wrong, and hence of one's moral responsibilities, relates to how one's actions affect others. Thus lack of empathy is understood to impede moral responsibility and, in a larger sense, moral personhood.

Autism complicates this version of moral being. Although autistic individuals may have difficulty with a natural sense of empathy towards others, through conscious effort and training, they can develop codes of behavior for themselves that take the implications of their actions towards others into consideration. This training begins, usually from the point of diagnosis, in the form of therapies and educational programs for autistic children. These children then adopt

the codes of behavior that they were taught and apply them in their lives outside of therapy. Thus, these codes of behaviour seem to implicate a moral responsibility in their actions. It comes hard to sustain any simple argument that moral personhood requires moral consciousness based on empathy which autistic individuals putatively do not develop.[13]

The 'problem' of inner disturbance

The term disturbance in English doesn't necessarily carry the same weight or meaning that it does in Amharic. For example, it is not uncommon to hear parents in Ethiopia describe their children as *rebash*, to describe children who are misbehaving (e.g. engage in behaviours with a kind of restless, troublemaking quality, behaviours such as fighting with other children, breaking objects or, more generally, disobeying what they are told). Alem's description of her son's state however repositions this sense of restlessness within the child. To say of someone *terebishwal* in Amharic is to describe that person as lacking calm and stability within him- or herself. It is to say, 'this person is experiencing an inner restless, some kind of agitation (in their thoughts, feelings, spirit), an inner tension perhaps escalating to the point of anger'. Notably, although an individual in such a state may behave in particular ways, this description points to that individual's inner experience.

While self-stimulating behaviours can be interpreted as a response to sensory input, they can also be interpreted as a response to that input in terms of its social meaning. For example, this disturbance from within can be interpreted as an emotional reaction to another's emotional state. Alem told me this story to explain that her son understands how she feels:

[13] This begs the question of how integral, or more specifically necessary, empathy is to our understanding of personhood.

He still does some things. He hurts himself, he hits and bites his index finger. *Yibesatchal* (lit. he gets upset). **He doesn't like loud noises.** The other day, we were waiting for a taxi and a drunk man approached us asking for money. I told him I didn't having anything because he is fully able-bodied, he can work to feed himself. He would just drink with it anyway. **This man start yelling at me and my son was ready to hit him.** He was stamping his foot, yelling, he was getting upset. **He could see that this man was hurting me.**

In this case, *yibesatchal* is a phrase that works with the phrase *terebishwal*, to describe a disturbance or unsettling feeling coming from within (terebishwal) and being expressed outwardly (yibesatchal). The 'things' that this boy does (hurting, hitting and biting himself) can be examples of self-stimulating behaviours. Further, a sensitivity to auditory stimuli (e.g. the stranger's yelling) resulting in those self-stimulating behaviours can be interpreted as a sensory overload. However, significantly, Alem interpreted her son's behaviour as a reaction to the social and emotional context of the man's yelling: it was that her son knew she was being made to feel uncomfortable and hurt.

The difference between understanding self-stimulating behaviours as a response to sensory input or as a response to that input in its social context is significant as it distinguishes the child's orientation to what is provoking the self-stimulating behaviours. When the child is described as *terebishwal*, or 'inwardly disturbed' the disturbance is understood as originating from within the child. By describing the child in this way, parents attributing to him or her some level of emotional autonomy. This ascribes depth to the child, framing him or her as more than a

reactive being. Instead, she or he is an emotive being, starkly different from the trope of the autistic child as withdrawn, isolated or trapped and disconnected.

In her description of her son's particularities in relation to his social awareness, Alem gave another example.

There's another thing he does. **When something is bothering him, he spits on it. If he sees a man or a woman on the street that bothers him, he will spit on them. He's picky about people.** When had a new housekeeper one time and he spat on her. She was shocked and said, 'you know what I don't even want to work here' because she thought he was always like this. The housekeeper we have now, when she met my son she would call him "abiye" and he likes her. **Her company doesn't bother him. He just wants love.**

She attributes to her son a certain kind of social ability, the ability to make judgements about people. The 'problem' at the core of her son's behaviours is not his sensitivity to sensory stimuli, instead his sensitivity is a demonstration of his thoughts and feelings. The 'problem' is learning to decipher what he means (in this case, to understand who he likes and dislikes) and to meet particular needs. This boy's behaviours, although inappropriate, are outwardly expressions of what he feels inside. In a way, beyond a reaction to different individuals, these behaviours are a means of communication. In framing the 'problem' this way, the 'solution' is then not developing strategies to cope with the child's lack of communication, but instead to develop strategies that acknowledge what and how the child knows to communicate to replace the existing inappropriate ones.

Describing their children as experiencing inner disturbances allows for an understanding of their child with a certain kind of depth. Their child, in this sense, is a being that processes input from his- or herself (i.e. his or her desires, emotions) as well as from their external environment with a human complexity, like any other person. This understanding breaks beyond the image of autism's child, a being deficient in ability to process their inner and external worlds, simply reacting to the stimuli around him or her.

Taking up again Hacking's concept of 'making up people', the nominal distinctions of lived experiences created by labels such as autism is significant here. In Ethiopia, while the category of autism has been implanted there, not least with the founding of the Joy Centre, the specifics of what counts as 'autistic experience' is being created within that context. As parents develop their understanding of autism through their experiences with their child, they are shaping what counts as 'autistic experience' or in other words forming what it means to be 'autism's child'. What has been described as autistic aloneness in the Western context is being understood as a kind of social sensibility.

Trajectories of categories: neurodiversity & 'autism's child'

In addition to the significance of parents in Ethiopia shaping their own understanding of autism—their own conceptualization of 'autism's child'— part of it resonates with a relatively recent reframing of autism in the West. The neurodiversity movement is relatively young (the term was coined in the 1990s) and advocates of this movement hold the radical view that autism and other neurological differences are not devastating disorders in need of curing or eliminating. They are instead part of the natural variation of the human condition— variation that can result

in unique challenges, to be sure, but also in unique strengths. The reason autism can be so debilitating, the argument goes, has more to do with society's lack of support, accommodation, and understanding than with autistics' atypical neurology. We should be working to create inclusive communities where autistics can flourish with (and perhaps because of) their autism, not trying to turn autistics into nonautistics." (Silberman, 2015, quoted in Jaswal, 2017)

In his work *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*, science journalist Steve Silberman argues that viewing autism as a lifelong disability that deserves support, rather than as a disease of children that can be cured is the oldest idea in autism research (2015, p.81). According to Silberman, based on autism's history, the person responsible for that idea is Hans Asperger, the pediatrician in Vienna whose case studies would later anchor what would come to be known as Asperger's syndrome. In Silberman's account, Kanner's case studies, and the resulting conceptualizations of the withdrawn autistic child and autistic aloneness, overshadowed Asperger, to the detriment of those who would be diagnosed with autism. Silberman argues that while Kanner's focus was on the autistic child's inability to connect to the world around them, Asperger developed a balanced perspective from his case studies, looking at both the social impairments and talents present. His approach to treating autistic people was to provide them with an environment where their strengths could be fostered and their challenges supported, the very core of the recent neurodiversity movement (Jaswal 2017; Hollin 2017).

In the context of my work, this argument is significant not as an explanation of what is happening at the Joy Centre (and more widely in Ethiopia) but instead as an illustration of the trajectory of autism as a category. Comparatively speaking, the way parents understand and seek

to care for autism at the centre is perhaps closer to a neurodiversity perspective, framing 'autism's child' with more depth and richness than the Western trope of the autistic child has. Looking at this category's journey from Leo Kanner's fixed diagnostic category to the development of autism as a spectrum (including Asperger's, non-pervasive developmental disorder) now to neurodiversity, Silberman's argument opens up the question of where current conceptualizations of autism would be if Asperger's work had dominated Kanner's. Now considering the conceptualizations of autism in Ethiopia, particularly considering the marker of inner disturbance, one may wonder if there is an advantage to this framework of autism. Where the neurodiversity movement calls out society's lack of support, accommodation, and understanding of autistics' atypical neurology, this has already begun in a much earlier stage in the category's trajectory in Ethiopia. From the orientation of Zemi's work to establish the Joy Centre while being a mother with a son who has autism to the way parents orient themselves in terms of their responsibility to understand what their child means when he or she is acting a certain way, there is a difference between Kanner's autism and 'autism's child'.[14]

Conclusion

Differently from how autistic children have been viewed in the "West" or in international biomedicine as represented in WHO's ICD standards, the explanation of these children as cognitively (and therefore emotionally) stunted or simply hypersensitive to sensory stimuli is not what I found at the Joy Centre. As demonstrated by the marker *terebishwal*, parents understand

[14] This is not to ignore that there is a cure mentality present among the parents. They did speak of hoping their child "goes back to normal". However, my focus is on the trajectory of autism, that in Ethiopia this category has had a different starting point and therefore will continue to shift and change in the future.

their children as being able to experience deep inner emotional states, to the extent that they perceive their children to be sensitive to the emotional and social context of the world around them and they work to know how to care for this sensibility. As a marker of 'autism's child', this way that parents are describing their children presents an interesting intersection with the way autism has been (from a sensory processing perspective) and is coming to be understood. In the neurodiversity movement, there is a growing conceptualization of people with autism, not as lacking in the richness of their inner worlds or ability to connect with their external worlds, but rather on the spectrum of neurological configurations, in which we have yet to fully understand those who fall beyond the neurotypical.

Conclusion

For the parents at the Joy Centre, over the course of their journeys in coming to know what autism is, they noticed significant differences in their children from how they were as they were growing up. They spoke of these differences in specific ways: *aff alfetam* [he has not untied his mouth], *aysemam* [he does not listen] and, *terebishwal* [he is disturbed]. Each of these, beyond being a sign of some difference, come together as markers of some fundamental change in the child. This fundamental change is summed up in the phrase "autism's child". With "autism's child", the parent acknowledges their son or daughter as inaccessible in particular ways: in the form of a 'tied mouth', an inability to listen, and experiencing inner disturbance. Saying that a child belongs to autism is evidence of that parent's struggle to care for their child. It is through that belonging that they find ways to care for their child.

In the previous chapters, I have attempted to show the ways in which Ethiopian parents have come (and are coming, as this is an ongoing process) to understand their children with autism. Notably, though autism as a biomedical concept has been introduced by way of the Joy Centre, I found that parents are developing their own understandings based on markers that are significant to them. Through each of the chapters, I have explored a significant marker of autism, drawing these directly from the stories and experiences of the parents I encountered at the Joy Centre. It is important to consider the way that the function and meaning of medical beliefs and practices are transformed when they are transplanted to a different context. The biomedical concept of autism is being transformed and reshaped as parents in Ethiopia work to integrate this newer information with what they already know and have experienced. As explored in chapter

one, the marker of a tied mouth is a significant one in part because of the historical understanding of this problem. That parents were up blamed and stigmatized for having children who did not or could not speak allowed for the recognition of this marker in the present context. However, as parents integrated what they knew about a tied mouth with what they are coming know and understand to be autism, this marker took on a different form. It became emblematic in terms of recognizing 'autism's child'. Further, in chapter two I discussed where instead of a cognitive interpretation of attention and learned behaviors, parents were focused on whether their child listens to them or not. As they were coming to recognize the difference present in their children, they developed the understanding that not listening or what may appear as disobedience did not hold the same meaning in 'autism's child'. There was a shift in terms of responsibility on the part of the parent to understand this marker and learn to accommodate it by following the model of the teachers. Additionally, significant in this aspect of the shaping of autism as a category in Ethiopia, questions of good parenthood (especially motherhood) arose that played into the conceptualization of the child as belonging to autism. In chapter three, the marker of inner disturbance fundamentally differentiates the way that autism is understood in Ethiopia compared to the West. Rather than adopt the trope of the isolated and withdrawn autistic child, parents understood their children as having an emotional depth that was evidence of their connection to the world and instead saw the problem to be the communication of that connection. In addition to this, the way Ethiopian parents have shaped what it means to be 'autism's child' is significant for what it says about the potential trajectory of this category. Considering the evolution of the biomedical category of autism in the West leading to the neurodiversity movement, there is significance in the way a category is introduced. As ideas surrounding

‘autism’s child’ continue to shift and transform and evolve, these three markers present a kind of starting point.

This conceptual framework also gestured to a question of what and where is the "problem" of autism? In a larger sense, one can see a reinterpretation of the 'problem' of autism from being a spiritual one to being introduced as a medical one. But even with that biomedical introduction, parents' overall focus on specific behaviours rather than cognition and general social competence points to a social rather than biomedical locus. Further, the markers are linked to specific questions about the " problem". When parents spoke of listening, they were speaking of a social problem in the sense that they found autism to be interfering in their social expectations of their children. In fact, beyond merely social, these expectations were value-laden (e.g. obedience) making the problem of autism a moral one as well. Especially when speaking of an inner disturbance, not only did the parents not take to the biomedical explanation of sensory processing and sensory overload but, by understanding the problem as a social one (wherein the lack is on the part of the parents in finding ways to understand and help their child communicate what they feel) parents are not only locating autism in the social but they are shaping autism child to be a kind of social and moral being.

One teacher who had been working at The Joy Center almost since its establishment, and had observed parents’ struggles over the years, explained to me, “After a while, it's not about autism, not really. Autism is this thing, an obstacle, a set of challenges, a hardship to endure and overcome. But the child does not need to be stuck in this certain state, in the depths of autism. Change can happen. ... To the point where parents forget about autism.” In a way, as parents shape and 'make up' what it means to be 'autism's child', they are focusing on their child.

Although they have adopted the word autism in the phrase 'autism's child', they have not adopted the entirety of this biomedical phenomenon. The ‘making up’ of people is tied to the context of lived experiences and the language used to create these categories. The words and phrases in Amharic that reference and describe autism, the language necessary for the creation of the category, are in the process of being developed and are creating, shaping, and making up a particular kind of child that fits in that category. These ideas are not static; knowledge in Ethiopia, as elsewhere, is constantly changing.

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