# "But it doesn't really have to do with the bilingualism": Family language policies in transnational families of bilingual autistic children 

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## Abstract

Family language policy (FLP) investigates family members' language ideologies, practices, and management strategies. With the growing number of autistic children exposed to bi- or multilingual environments, there is a gap in the existing body of FLP research that has not focused before on speaking and non-speaking autistic children from transnational families. This study, therefore, aims to determine to what extent existing FLP frameworks can adequately capture the lived experiences of families with bilingual autistic children. This mixed method study uses an online parental questionnaire to investigate which language and modality policies and practices are prevalent in transnational families with bilingual autistic children. Thereafter in semistructured interviews with eight parents, it explores other potential factors that affect parental decisions about bilingualism. The study further aims to explore other broader ideologies and discourses about autism and bilingualism in the parental accounts. The results suggest that most parents of bilingual autistic children shared positive views about bilingualism and linked language challenges to autism, not bilingualism. However, their language practices and management strategies were not always consistent with their views on bilingualism. The results of the interviews indicate that additional diagnoses, spoken language proficiency, the amount of required additional support, misrecognition of early diagnosis, professional recommendations, and access to socioeconomic resources were other factors influencing parental decisions about bilingualism. As a result, I argue that FLP as a theoretical framework fails to capture certain aspects of the families' lived experiences and to address ableist injustices or offer any remedies against them. After examining Nancy Fraser's theory of redistribution and recognition and Boaventura de Sousa Santos' notion of "abyssal thinking", this thesis highlights the importance of developing an innovative theoretical framework that can incorporate FLP, social class, other forms of difference, and the neurodiversity movement as a transformative remedy to address ableist injustices experienced by bilingual autistic children and their families. This thesis also proposes to use the terms "semiotic practices" and "semiotic management" as part of the FLP framework to incorporate other modalities than spoken language. It also introduces the term "ableist thinking" for descriptions of abyssal thinking related to autism. The proposed model can be used by practitioners working with autistic children and their families and potentially improve their lived experiences and access to bilingual resources.

## Keywords

Autism, bilingualism, multilingualism, ideology, transnational families, family language policy, neurodiversity, ableism

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## List of abbreviations

| Abbreviation | Definition |
| :--- | :--- |
| AAC | Augmentative and Alternative Communication |
| ADHD | Attention Deficit Hyperactivity Disorder |
| ASD | Autism Spectrum Disorder |
| ASL | American Sign Language |
| FLP | Family Language Policy |
| MajL | Majority Language |
| MajL@H | Majority Language at home |
| ML | Minority Language |
| ML@H | Minority Language at home |
| MLU | Mixed Language Use |
| ODD | Oppositional Defiant Disorder |
| OPOL | One Person, One Language |
| PECS | The Picture Exchange Communication System |
| WEIRD | Western, Educated, Industrialised, Rich, and Democratic |

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## 1. Introduction

I think language gives you different perspectives of the world. Language is a reflection of a way of thinking and of a culture. Being exposed to different ones opens the windows for you to different worlds. I mean, when you start wondering, why is this called this or where does this expression come from? When you realize that different ways of expressing the same feeling, I think it gives you wider horizons. I don't know. I mean, I think it worked that way for me. (Isabella, Interview 7).

Isabella shared this thought about the importance of bilingualism ${ }^{1}$ with me during an interview about her now-adult autistic son. I did not include this interview in my final analysis since her son Fredrik was diagnosed in his late teens, and most of the decisions about bilingualism made by his parents were not affected by his diagnosis. Nevertheless, Fredrik's family is a typical transnational family that I ended up studying for this thesis: the parents were an intermarried couple with ties to three countries. As a result, the family was using English and Swedish as their home languages. Isabella decided not to speak Brazilian Portuguese, her native language, at home since she believed and was told that "three languages were too much". Is Isabella's experience as a minority mother in a transnational family typical or an exception? What happens if you add autism as a part of such a family's lived experience? This thesis will attempt to shed more light on it.

Autism is a lifespan neurodevelopmental condition that affects a person's social, emotional, communication, and behavioral spheres. Based on the diagnostic criteria provided by the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM5; American Psychiatric Association, 2013), Autism Spectrum Disorder (ASD) leads to deficits in verbal and nonverbal social communication and interaction, as well as to restricted, repetitive behaviors and interests. The amount of support required by an autistic person varies greatly depending on how much it interferes with their daily life. Autistic people have varying levels of verbal language ability, with some being completely nonverbal and others speaking fluently. Many autistic people are part-time or full-time users of non-aided or aided Augmentative and Alternative Communication (AAC).

Researchers are still trying to work out how learning an additional language affects children across their lifespan. Overall, there is agreement that bilingual children who develop neurotypically have some developmental advantages (Fan et al., 2015; Liberman et al., 2017). More recent attention has focused on the vocabulary size of autistic bilinguals with the results indicating that there is no significant difference between the vocabulary sizes of monolingual and bilingual autistic children reported by parents or the examiner (Valicenti-McDermott et al., 2013).

[^0]Despite the recent research findings, many parents and professionals hold the unsupported belief that exposure to additional languages may harm the language development of autistic children (Hambly \& Fombonne, 2012; Reetzke et al., 2015; y Garcia et al., 2012; Yu, 2013; Yu, 2016; Zhou et al., 2019). However, a growing body of evidence refutes this claim (Hambly \& Fombonne, 2014; Ohashi et al., 2012; Reetzke et al., 2015). As a result, there is a discrepancy between contemporary research findings and the recommendations made to parents about bilingualism for their autistic children. This causes concerns among parents when deciding which languages to use in their households (Howard et al., 2021; Kay-Raining Bird et al., 2012; Reetzke et al., 2015; Yu, 2013).

Some parents of autistic children are informed that the bilingual environment might delay their child's language development ( $\mathrm{Yu}, 2016$ ). These negative beliefs may result in parental attempts to turn their child's language environment into a more monolingual one, depriving it of potential developmental benefits. According to some researchers, educational professionals still recommend parents of children with developmental disabilities to abandon their home language in favor of the dominant majority language (Cheatham \& Lim, 2020; Jegatheesan, 2011; Jordaan, 2008). This is still happening even though recent studies of language development in bilingual autistic children refute many negative beliefs and myths about bilingualism and developmental disabilities (Dai et al., 2018; Hambly \& Fombonne, 2012; Ohashi et al., 2012; Reetzke et al., 2015).

The above-mentioned studies were predominantly approaching bilingualism and autism from the perspective of language acquisition and did not focus on parental views about bilingualism. The process of making decisions about language use at home is known as family language policy (FLP) (King et al., 2008; King \& Mackey, 2007). The existing body of literature on language development and maintenance in bilingual autistic children is also primarily concerned with speaking children (e.g., Hambly \& Fombonne, 2012; Ohashi et al., 2012; Reetzke et al., 2015; Valicenti-McDermott et al., 2013; Zhou et al., 2019). As a result, there is a significant research gap in studies of bilingual minimal speakers, non-speakers, and part-time or full-time AAC users on the autism spectrum, particularly those from transnational families. Since it is believed that FLP is the most critical domain in language maintenance (Smith-Christmas, 2016), this study focuses on the family as a micro level of analysis but understands the micro as constituted in and through wider socio-political and economic processes.

Studying language practices and policies within a family as a unit is crucially important since "the family context is a critical initial stage in children's language socialization and their closest language ecology" (Schwartz, 2020, p. 195). However, while the family remains a community of practice (Wenger, 1999) with "a shared repertoire that develops through mutual engagement as a mode of belonging" (King, 2019, p. 44), it is constantly influenced by multilingual language policies, social media, technology, transmigration (King \& Lanza, 2019; Lanza, 2021; Lanza \& Gomes, 2020), and other family-internal strategies (Slavkov, 2021). Families become even more dynamic due to social media and online communication tools, as they transition from a traditional sociolinguistic private domain to a public one (Lanza \& Gomes, 2020; Palviainen, 2022). It is even more important as bilingual autistic children and their family members will benefit greatly from
not encountering any issues related to bilingualism and reaching the so-called Harmonious Bilingualism (De Houwer, 2020).

As a result, the goal of this thesis is to investigate whether FLP is a suitable framework to describe the lived experiences of transnational families with bilingual autistic children and to examine their reported language practices, ideologies, and management strategies as part of this framework. An online parental questionnaire and eight semi-structured interviews with parents were used to study the languages and modalities used by families at home, as well as their attitudes towards bilingualism, and advice given by educational and healthcare practitioners. The parental interviews provide a deeper understanding of how these families' configurations and practices are "shaped by the historical bodies" (Palviainen, 2022, p. 125) (their lived experiences) and the role of both autism and bilingualism as part of their lived experiences. The analysis of qualitative data follows Block's (2017) advice to every researcher studying language identity to use class and race as major concepts. By seeking to investigate the intersectionality between class, medical and social models of disability, neurodiversity, and ideologies of autism and bilingualism, this study tests the limits of existing theoretical frameworks for understanding the mechanisms of autism recognition and redistribution.
My research can assist in determining the language perceptions and practices of transnational families with bilingual autistic children. It emphasizes the need for a new robust framework that considers a decolonial approach to FLP (Gomes, 2018), neurodiversity, and social class. While acknowledging the importance of race, ethnicity, and other forms of difference, the scope of the study only allowed for a focus on three major axes of difference: neurodiversity, bilingualism, and class. I hope that this research may also encourage official organizations, AAC software developers, and speechlanguage pathologists to provide more assistance to families raising autistic children bilingually.

### 1.1 A note on the language used in this thesis

Throughout this thesis, I use the identity-first language when describing autism. Thus, instead of the more common terms in applied linguistics "children with autism" or "children with ASD", the reader will find language like "autistic children", "on the autism spectrum", and other identity-first terms. The language describing autism is constantly changing, evolving, and is a matter of heated debate within the autistic and non-autistic communities (Bottema-Beutel et al., 2021; Fletcher-Watson \& Happé, 2019). I did, however, use the term ASD in the questionnaire for this thesis, as it was created for parents of autistic children from various countries where preferences for identity-first language might not be as prevalent as in the majority of English-speaking countries. I tried to move away from deficit-based language when mentioning the specific needs of autistic children. It was more challenging than I expected, as the author comes from the field that uses terms like "language development," "speech delay", etc. in many publications. The reader will see traces of these language debates within the next chapters. I am a firm believer, that we, as academics, should enforce the changes ourselves and
move away from the "but this term is more commonly used" rhetoric by respecting and using the language preferences of autistic people.

## 2. Literature review and theoretical framework

### 2.1 Autism and bilingualism

Parents of autistic children often face a choice of whether to raise their children bilingually or not. This decision is an integral part of transnational families' lived experiences. Can autistic children be successful language learners? Is it smart to add another language if the child already struggles with one? Will exposure to more than one language confuse an autistic child? What to do if the autistic child does not speak at all? These are some of the questions that interest many researchers in the field of language acquisition. It is believed that neurotypically developing bilingual children have some developmental advantages in comparison to their monolingual peers (Fan et al., 2015; Liberman et al., 2017). Some studies showed that bilinguals have an advantage in certain areas of executive functioning when compared to monolinguals (Bialystok, 2011). Parts of this executive functioning are thought to compensate for some of the disadvantages of bilingualism (Peets \& Bialystok, 2010), such as a possible disadvantage in lexical retrieval (Bialystok et al., 2008). However, if one wants to compare lexicon sizes in bilingual and monolingual neurotypically developing children, the results are mixed: some researchers found no difference in their sizes (De Houwer et al., 2014; Legacy et al., 2018; Pearson et al., 1993), while others concluded that bilinguals have a smaller vocabulary size than monolinguals (Hoff et al., 2012; Marchman et al., 2010; Oller \& Eilers, 2002).

Nevertheless, a meta-review of research comparing language development in bi- and monolingual autistic children found that bilingual children on the autism spectrum are not significantly different from monolinguals, with most measures favoring monolingual autistic children only marginally (Lund et al., 2017). Other reviews of the literature found no evidence of any negative consequences of raising bilingual autistic children in terms of its effects on diagnostic behaviors (Wang et al., 2018) or language development (Drysdale et al., 2015). Additionally, bilingual autistic children seem to produce more prelinguistic cooing and proto-imperative gestures (Reetzke et al., 2015; ValicentiMcDermott et al., 2013) and show fewer set-shifting difficulties compared to their monolingual peers (Gonzalez-Barrero \& Nadig, 2019). Thus, it can be concluded from the growing body of research in language acquisition, that there are no significant differences between bilingual and monolingual autistic children. This shows that any recommendations to "remove" a language from an autistic child's environment or to avoid additional language learning are not grounded in academic research.

Moreover, recent articles ${ }^{23}$ based on the findings from the University of Geneva (Peristeri et al., 2021) even claim that bilingualism "makes up for deficits in theory of mind and executive function" (Neuroscience News, 2021). Many language acquisition researchers, therefore, agree that autism does not affect the development of cognitive skills and might even lead to advantages in certain aspects of these skills (Digard \& Davis, 2021; Montgomery et al., 2021; Sharaan, 2021). Additionally, recent research also suggests that adult autistic bilinguals are more satisfied with their social life and have a better connection with their identities (Digard et al., 2020). Adult autistic bilinguals also report many educational, career, and leisure benefits of bilingualism, including improvements in relationships with friends and family, as well as members of the autistic community from other countries (Nolte et al., 2021).

Overall, according to the recent list of recommendations for clinical practitioners and educators (Digard \& Davis, 2021), the autism research findings suggest that "bilingualism does not negatively impact autistic people and may provide benefits for cognitive and socio-emotional development".

Despite this overwhelming evidence that bilingualism does not have any negative effects on autistic children, these findings seem to be rarely transferred into direct recommendations to parents who must decide whether to raise their autistic child monolingually or bilingually. To my knowledge, the only attempt to make these findings accessible to parents and clinical practitioners was made by Digard and Davis (2021), who published a guidance document with a summary of findings about bilingualism and autism and transformed it into a downloadable brochure in ten languages ${ }^{4}$. This step in moving from research finding to making recommendations for people who could directly benefit from them is, in my view, one of the most important outcomes of research that addresses demands for what Fraser (1995) calls transformative remedies.

Overall, it seems that the current research in the field of bilingualism and autism with its over-focus on "successful language acquisition", comparisons to neurotypical bilinguals or autistic speaking monolinguals as golden standards is shifting too slow toward the neurodiversity movement and neurodiversity-affirming practices. One can argue if there is any shift at all, apart from a few researchers who are proponents of the neurodiversity movement. The latter have argued that autism research and intervention practices must be aligned with the neurodiversity movement (Leadbitter et al., 2021) - social justice and civil rights movement that intersects with the disability movement and advocates for full inclusion of all neurodivergent people (Hughes, 2016).

Juxtaposed to the neurodiversity movement is what I would call "ableist injustice" that belongs to other axes of injustices possibly faced by bilingual autistic children from

[^1]transnational families. Such injustices are rooted in the medical model of disability and policies and practices exercised by modern states that transform autistic people into "outcasts in the guise of protecting and furthering everyone's own good" (Kulick, 2022) by comparing them to "normal" people. Consequently, some researchers argue that just like the concept of a "normal" person, autism is a social construct since "autistic people are grouped together by very real characteristics which have been assigned meanings that change across time and cultures" (Botha \& Gillespie-Lynch, 2022, p. 5).

Thus, the neurodiversity movement as a transformative remedy for ableist injustices is closely connected with the two paradigms of social justice - recognition and redistribution (Fraser, 1995). While the former focuses on identity and is considered to be a remedy for cultural and symbolic injustices, the latter is a remedy for socioeconomic injustices (Block, 2018; Fraser, 2008; Fraser et al., 2003). Fraser (1995, 2006, 2008) argues that people who suffer from both types of injustices require both recognition and redistribution. In later publications, she also added a third dimension to redistribution and recognition - representation (Fraser, 2006, 2008). This additional dimension "encompasses "meta-political injustices" that arise when the division of political space into bounded polities frames what are actually transnational injustices as national matters" (Olson, 2008, p. 10). While she does not use disability or neurodiversity in her examples, I believe this framework can be applied to the ableist injustices experienced by autistic people. Following Fraser's framework (2008), autistic people belong to the socalled bivalent collectivities that "suffer both socioeconomic maldistribution and cultural misrecognition in forms where neither of these injustices is an indirect effect of the other, but where both are primary and co-original" (p.21).

While recognition and redistribution have been previously applied to language education research (Block, 2018) and the context of disability research with a focus on the deaf community (Danermark \& Gellerstedt, 2004), it has not been studied on the micro-level of home language management in families with autistic children.

### 2.2 FLP

The modern family is not a fixed entity, it is diverse and dynamic and has more dimensions than the "traditional" nuclear family. This term incorporates many family structures, including same-sex couples, polygamy, adoptive families, single parents, widowers, divorced parents, multigenerational families, and many others. Families are often chosen as a unit to study language policies and practices since they usually form the first and one of the most important language environments of a person. According to Lanza and Gomes (2020) "family can be conceptualized as a space along the private public continuum of arenas of social life" (p. 165). Thus, family is usually studied as a representation of micro policies, while political and educational policies form macro and meso levels of policymaking (Curdt-Christiansen \& Gao, 2021). Since all these levels interact and impact each other (Schalley \& Eisenchlas, 2020), families are continuously influenced by decisions on both macro and meso levels. Despite that, the majority of FLP studies are focused on the micro level of analysis.

One of the best definitions of FLP as a field was provided by Yu (2016): "FLP is the study of what people think about language, what they wish to do with language, and what they actually do with language" (p. 426). What language do family members use for their daily routines, for reading, watching videos on streaming platforms, during Zoom conversations with grandparents and other relatives, and what language do they choose when installing a new videogame or buying a family boardgame: all these small but important decisions made by a family are part of FLP. Much of the FLP scholarship is built upon Spolsky's tripartite model (2004, p. 5): language practices (how family members use language), language ideology (what family members think about languages), and language management (what they attempt to do to acquire and maintain language). Despite the popularity of this model, there is a lot of arguing about the strict definitions of each element within it. For example, Schwartz (2020) argues for the importance of distinguishing between home language policies and practices in her extensive review of recent scholarship on home language maintenance. According to her, home language policies refer to family language management, while home language practices refer to daily routines in language use at home. As a result, FLP is inextricably linked to the home language model and investigates both language policies and practices at home.

A lot of FLP scholarship is framed around named languages, however, Spolsky (2004, p. 8) believed that language policies do not necessarily operate within named languages alone. In his later work, Spolsky (2022) switched to using the term language repertoires instead of named languages when describing people's lived experiences. However, he points out that this term "doesn't mean giving up on naming languages" (Spolsky, 2022, p. 10), since named languages "occur not in practices, but in beliefs: their existence is the first belief of speakers and linguists; they are also the focus of management, which depends on values assigned to identified named language varieties" (p. 12). Additionally, language practices and beliefs are constantly influenced by a variety of non-linguistic internal and external factors such as politics, demography, religion, culture, and other social factors (Spolsky, 2004, p. 6). According to Spolsky (2022, p. 12), a person's language repertoire is formed by the languages they are exposed to, whereas their language ideology is shaped by their attitudes toward speakers and the potential usefulness of these languages. Does this explanation apply to a non-speaking autistic child from an intermarried family where nobody uses the majority language at home while the child is exposed to it through the language of schooling? While it presents a combination of external (the language of schooling) and internal (what languages are used at home) factors that continuously shape this child's language repertoire, it seems somewhat limited within the context of language ideologies. One could argue that the notion of language ideology as described by Spolsky is greatly influenced by language availability - let's say that this non-speaking child uses high-tech AAC, does she have access to an AAC in her minority language or the majority language only? Just from this example alone, it is clear that parents of autistic children are forced to make certain decisions based on language ideologies that operate strictly within named languages. These micro level decisions are forced by the meso level - an AAC developer company that decides in what languages to build their AAC app or device. This decision, in its turn,
is based on the macro level - what named languages are used in their country or can lead to a lot of profits.

In terms of language models that are central to the FLP scholarship and minority language maintenance, OPOL (one person, one language) is, undoubtfully, one of the most popular and well-studied (De Houwer, 2009; Slavkov, 2021) models. It presupposes that a child experiences a balanced language input in two different languages spoken by two parents at home: parent X speaks language X , while parent Y - language Y . Ideally, this should lead to balanced bilingualism, as their child is supposed to address parent X in language X , and parent Y - in language Y . However, this is not always the case, as mothers are often the main caretakers of children, as a result - the language input can often be unbalanced towards the mother's language.

Other models describe situations when the family speaks exclusively minority language at home (ML@H), majority language at home (MajL@H), or mixes both minority and majority languages (mixed language use) (Slavkov, 2021, p. 92). While OPOL is considered to be the most balanced model, it does not necessarily mean that other models lead to less successful minority language maintenance or more "passive" bilingualism.

As a result of this fixation on particular family language models, the research has approached the FLP from various angles to answer the question - which model is the best? There is some evidence to suggest that the minority language-speaking caregiver and the amount of time spent around them is the key answer to that question (SmithChristmas, 2016). Thus, minority language speaking mothers are frequently linked to a successful minority language maintenance, especially in intermarried families (Doyle, 2013), since mothers are often children's primary caregivers (Smith-Christmas, 2016). "Minority mothers" are often doing the "invisible work" of raising children and do the "logistics" for maintaining long-distance connections with their families back home (Doyle, 2013; Palviainen, 2022). Having older siblings is also associated with an important role in minority language maintenance (Smith-Christmas, 2016; Yates \& Terraschke, 2013). Some findings also suggest that the quality and quantity of language input at home play a vital part in successful language maintenance (De Houwer, 2007, 2011; MacLeod et al., 2013; Mishina-Mori, 2011); other findings show that the input consistency such as avoiding code-switching might be a crucial factor in children's future minority language use (Byers-Heinlein, 2013; Kasuya, 1998).

Overall, it seems the FLP scholarship has shifted from studying bilingual language acquisition to using a variety of sociolinguistic approaches to explore meaning-making in dynamic, diverse, transnational, and multilingual families (King, 2016; King \& Lanza, 2019; Lan Curdt-Christiansen \& Huang, 2020; Lanza \& Gomes, 2020; Mirvahedi, 2021; Palviainen, 2022). This study will be also positioned within this emerging framework since it is hard to examine language acquisition in such a diverse group of participants from transnational families, and different age groups, with various additional diagnoses and different language repertoires. Successful language acquisition often operates from a notion of the so-called "successful learning", which is a problematic definition, especially in the context of autistic children, whose families and educators face different goals in their developmental stages. Thus, for some "successful acquisition" will look like
learning to speak a second language, while for others - learning to type in it or pushing a button with a picture of candy when asking their mom for a candy. Is a child who spent five years learning how to form a phrase with his high-tech AAC less of a "successful learner" than a child who reached a pre-intermediate level of English as his second language? Of course not, despite what the field of second language acquisition might tell us. These definitions are deeply problematic and rooted in deficit discourses and monolingual bias (Cheatham \& Lim, 2020, p. 406). Just like the medical model of disability focuses on individual deficits in comparison to neurotypical people, so does second language acquisition with its constant comparison of language learners to native speakers. Given the above-mentioned issues, the following part of this thesis is focused on the social model of disability as a macro level affecting FLPs of translational families with autistic children. However, the thesis as a whole does not follow either medical or social models of disability but aligns itself with the neurodiversity paradigm that envisions autism as an identity and "an embodied disability with aspects of impairment" (Botha \& Gillespie-Lynch, 2022, p. 2) that requires both recognition and redistribution.

### 2.2 Autism and FLP

According to some researchers, educational professionals still advise parents of children with disabilities to abandon their native language in favor of the majority language (Cheatham \& Lim, 2020; De Houwer, 2021; Jegatheesan, 2011). There are two major myths about bilingualism and children with developmental disorders (DD): bilingualism causes even more significant language delay, and bilingual students with DDs should only attend school in the majority language (Cheatham \& Lim, 2020). If immigrant families choose the majority language-only approach at home, the belief that children with DDs should not be exposed to learning additional languages may result in fewer interactions in the minority language (De Houwer, 2021; Lund et al., 2017).

While not grounded in the FLP framework or focused on "successful" bilingualism, KayRaining Bird et al. (2012) were one of the first scholars to include questions about reported attitudes towards bilingualism in families with autistic children. The main takehome message from this study was to confirm that families with autistic children receive a lot of conflicting advice from professionals about bilingualism. However, Kay-Raining Bird et al. (2012) were predominantly focused on spoken language and did not consider the language of devices, screen time, reading, etc. to be part of their analysis (even though their questionnaire investigated such language practices) when labeling their participants' families as monolingual or bilingual. Since some autistic children's preferred modalities were gestural or visual, such a focus on spoken language and language acquisition is not representative of non-speaking or minimally speaking autistic children. Even though the study (Kay-Raining Bird et al., 2012) was conducted ten years ago, it can be assumed that the influence of the digital content was as important as it is in the 2020s. Despite the argument about the influence of screen time on language development and the need to differentiate active language use from language consumption (Little, 2020, p. 268), languages encountered through screen time should be counted as language exposure at home for autistic children. Thus, this thesis attempts to differentiate between different
uses of autistic children's screen time and includes it in the analysis of FLPs since it can facilitate language learning (Little, 2020, p. 263).

The need to include screen time and digital content consumption in FLP studies is also linked to the broader need for a better description of transnational families' lived experiences. While most FLP studies were built upon Spolsky's model (2004), there is a slowly emerging scholarship trying to approach the experiences of bilingual families from a more critical perspective. For example, Gomes (2018) provides a thorough examination of FLP as a field of study; he concludes that it is kept within both geographical and theoretical boundaries of the Global North and does not address transnational Southern families and their lived experiences. After examining the links between language, communication, and coloniality, Gomes (2018) proposes a critical decolonial approach to FLP that "underscores the intersectional dimensions of social categorizations such as gender, race, and class, while attending to the political and economic dimensions of the transnational centre-periphery divide" (p. 62). This intersectionality links the predominant theoretical framework of FLP with abyssal thinking (García et al., 2021; Santos, 2007, p. 45) that draws an imaginary line dividing contemporary social realities into two realms - "this side of the line" and "the other side of the line". While the social reality of this side of the line is distinctive and visible, it is "grounded on the invisibility of the distinction between this side of the line and the other side of the line" (Santos, 2007, p. 46). As a result, this abyssal thinking can be extended to language and language ideologies that construct different "orders of visibility" (Kerfoot \& Hyltenstam, 2017) and racialized speaking or listening subjects (Flores \& Rosa, 2015). The invisible abyssal line is occupied by the so-called White listening subject (Flores \& Rosa, 2015; García et al., 2021), while the other side of the line is often invisible and contains the lived experiences of racialized bilinguals (García et al., 2021).

While Flores and Rosa (2015) focused their research on raciolinguistic ideologies that "perpetuate the conaturalization of language and race, such that fixed, racialized perceptions of speakers influence how the listening subject interprets linguistic variation" (Martin et al., 2019, p. 24), their understanding of white gaze, speaking, and listening subjects not "as a biographical individual but as an ideological position and mode of perception that shapes our racialized society" (Flores \& Rosa, 2015, p. 151) can be used to describe what I propose to call ableist gaze, ableist speaking, and ableist listening subject. Just as the white speaking and listening subject is linked to monoglossic language ideologies and traits associated with "whiteness" (Flores \& Rosa, 2015; Fraser, 1995), so is the ableist speaking and listening subject linked to the notion of social and cognitive "normality".

The degree to which autistic bodies and voices are visible and audible is constantly influenced by the ableist gaze and ableist listening subject. Both ableist gaze and listening subject "render some types of knowledges, practices, repertoires, and bodies more legitimate, and therefore more visible, and thus construct different orders of visibility" (Kerfoot \& Hyltenstam, 2017, p. 8). Indeed, one can see signs of abyssal thinking perpetuated by the ableist gaze and listening subjects in autism research and advocacy. This is especially evident in the research that critiques the neurodiversity paradigm as
favoring autistic people who require less support, can speak, and are not intellectually disabled (Baron-Cohen, 2019). These debates within the autism research community and the autistic community itself about who has the right to represent the autistic community and should benefit from recognition and redistribution are linked to both orders of visibility and the desire "to govern by means of exception" (Kulick, 2022). Thus, they are silencing those autistic individuals who cannot be assigned to a homogenous category of autism (Botha \& Gillespie-Lynch, 2022). In a nutshell, people who critique the neurodiversity movement seem to miss its core aim that "neurodiversity is about the deserving dignity which should be afforded to all people despite neuronormative ideas of functioning and traditional constructions of independence and productivity" (Botha \& Gillespie-Lynch, 2022, p. 4).

From this perspective, in the same way as many autism researchers are focused on the notion of autism as an opposite to "normality", so is most FLP scholarship trapped inside monoglossic language ideologies where languages are conceptualized as fixed entities (Gomes, 2018). An alternative, more heteroglossic perspective that incorporates translingual practices would enable the use of notions such as translanguaging (García et al., 2021) and could transform the FLP field of studies (Gomes, 2018). Similarly, the neurodiversity movement's counter-normative understanding of autism could bridge this invisible abyssal line between neurotypical and autistic people.
In his later work, Spolsky (2022) addresses some of the critiques of his model by shifting the focus toward the language repertoire of an individual. However, he has not rushed into aligning himself with "supporters of language diversity and of minority languages" but rather alerts them to the need "to modify popular beliefs and ideologies in the hope of persuading powerful language managers and the general public to accept the positions they advocate" (Spolsky, 2022, p. 200). Thus, he believes that before offering any "grassroot response", linguists should establish a dialogue with people and organizations operating from the position of named languages. Furthermore, this "rethinking" of his model is tainted by several aspects of abyssal thinking still present in his work. They are especially evident in his descriptions of selecting a child's external linguistic environment where "good neighbourhoods" are supposed to provide a better influence on a child's language acquisition. It is not clear whether the existence of "good neighbourhoods" for language learning presumes parallel existence of some "bad neighbourhoods" in his analysis. Nevertheless, the juxtaposition draws a line dividing the influence of "good neighbourhoods" that "leads" to successful language acquisitions from "the Other" neighbourhoods.

The link between "good neighbourhoods" and OPOL studies brings us to the next angle of FLP critique. So far, research on family multilingualism has predominantly focused on three types of families: OPOL, immigrant families, and families from autochthonous communities (Gomes, 2018; Smith-Christmas, 2016). However, OPOL studies cannot be addressed outside the notion of social class, as families who employ this strategy can be usually identified as middle-class. Like Gomes (2018), Juvonen et al. (2020, p. 41) conclude that all present scholarship in home language maintenance studies has
developed a research bias towards the so-called WEIRD (Western, Educated, Industrialised, Rich, and Democratic) populations.
Research shows (Smith-Christmas, 2016) that OPOL studies focus on countries where the minority language of a family could be classified as a majority language (i.e., English in Scandinavian countries (Hult, 2012)). On the other hand, "belonging to an immigrant group means that the speakers and therefore their language most likely does not afford the same prestige as do the 'minority' languages in OPOL studies" (Smith-Christmas, 2016, pp. 7-8). Thus, the problems with minority language maintenance in OPOL families are not caused by their structural location, but rather by family decisions and practices. In contrast, immigrant families are subject to a broader range of socioeconomic and political factors, all of which influence their FLP.

Such a narrow focus on OPOL family research is especially problematic within the context of autistic people since children from minority groups are less likely to be part of early intervention services (Lund et al., 2017; Morrier \& Gallagher, 2012). This presents a challenge for the potential early identification of autistic children. Moreover, the belief that children with DDs should not be exposed to learning other languages may result in fewer interactions in minority languages within the immigrant families with autistic children if the family decides to speak only the majority language (De Houwer, 2021) at home. Being often unable to receive high-quality majority language input at home, such children are at higher risk of losing their initial competency in their minority language (Lund et al., 2017).

Overall, critiques of both autism and FLP research signal a pronounced need for an intersectional approach to bilingualism and autism by "exploring autistic identity development in relation to the development of other marginalized identities" (Botha \& Gillespie-Lynch, 2022, p. 2). As a result of all the above-mentioned limitations and critiques of FLP as a dominant theoretical framework, I decided to focus on autistic children from an intersectionality perspective of a transnational family that has "living arrangements spread over two or more countries, has an active desire to maintain family relations, and experiences important interconnectivity across and beyond national borders" (Palviainen, 2022, p. 128). This study is also positioned alongside Palviainen's (2022) definition of FLP as an "explicit and overt as well as implicit and covert planning" (p. 132) in family constellations in terms of their language use, and both offline and online practices regulated by individual needs in additional support of an autistic family member.

## 3. Research aim and questions

A growing body of research on parental beliefs about bilingualism in autistic children shows that parents have mixed feelings about the benefits or drawbacks of bilingualism for their children (Howard et al., 2021; y Garcia et al., 2012; Yu, 2016). However, to the best of my knowledge, no prior attempts have been made to link research on these beliefs
with the critical FLP framework to study parental perceptions regarding bilingualism in autism. Similar to Yu (2016), who points out that the concept of isolating one language from another within a speaker's full linguistic repertoire is a "formalistic view" that has little to do with their bilingual lived experiences (p. 425), I am situating my study within a heteroglossic language ideology. My research pays particular attention to families with non-speaking or minimally speaking bilingual autistic children. Following Gomes' (2018) critique of Spolsky's model, I believe it to be insufficient to describe the needs of autistic bilinguals. Thus, this research aims to find how to further expand the already existing FLP framework by including factors related to both autism and class. These factors are often linked to abyssal thinking, which from one side incorporates both racialized bilinguals, as well as non-speaking bilinguals, bilingual minimal speakers, bilinguals with situational mutism, and full- and part-time bilingual AAC users. From the other side, this abyssal thinking might operate not only from the perspective of the white listening subject but also from the ableist listening subject.

As a result, my thesis attempts to answer the following main research question:

## To what extent are current FLP models able to capture all the lived experiences of transnational families with autistic children?

To answer this question, the following set of sub-questions needs to be answered first:

- What family language practices, ideologies and management strategies are reported in questionnaires and interviews by transnational families of bilingual autistic children?
- What factors other than language(s) affect parental decisions about bilingualism?
- What broader ideologies and discourses of autism and bilingualism are present in parental accounts? More specifically, how do FLPs and ideologies of class and autism intersect in transnational families' lived experiences?

To answer these sub-questions, I will be looking into additional diagnoses and required support for each participant's autistic child. Based on previous research on language beliefs of families with autistic children (e.g., Howard et al., 2021; Yu, 2016), I want to investigate whether parents of bilingual non-speaking autistic children receive stricter recommendations regarding their home language, favoring the majority language in their country of residence. This study also aims to investigate the presence of abyssal thinking in parental discourses: I want to see to what extent the medical, social, and/or neurodiversity models of disability operate in parental discourses and intersect with class and other forms of difference. By investigating how losing old class positions and gaining new ones, what Block (2017) calls declassing and reclassing, can influence access to educational and medical resources, I explore the ways these changes shape the FLPs of transnational families with bilingual autistic children. I then analyze the intersectionality between autism, bilingualism, and class through the discussion of recognition and redistribution issues (Block, 2018; Fraser, 1995). This analysis can potentially provide insights into how additional diagnoses, verbality, social class, and other forms of
difference "impact experiences and development across the lifespan" (Botha \& GillespieLynch, 2022, p. 6).

## 4. Data and methods of analysis

The central research question is answered using both quantitative and qualitative data from the parental questionnaire and interviews. An online questionnaire was created to investigate variation within language environments of families with bilingual autistic children, as well as the declared family practices and attitudes towards bilingualism (see Appendix A). The term "language attitudes" was used as a concept that might be familiar to participants and therefore aid in the collection of data on their feelings and beliefs about bilingualism. The larger language ideologies that shape these feelings and beliefs were explored as part of the qualitative data collected during the interviews. Here the goal was to understand how parents' "beliefs and feelings about language are constructed from their experience as social actors in a political economic system" (Kroskrity, 2016). The questionnaire also investigated what recommendations practitioners made to families and asked for information on the family's entire linguistic repertoire, including all modalities. At the end of the questionnaire, the participants were asked to take part in a follow-up semi-structured video interview. Both the questionnaire and follow-up interviews aimed to understand how communication is managed through the various modalities used within a family. While the questionnaire was supposed to provide more facts about the participants, I was hoping to elicit more information about language and autism ideologies through interviews, which are normally filled with examples of the so-called symptomatic talk - "talk that expresses more about how one feels about a topic than it does facts relating to the topic" (Block \& Corona, 2019, p. 15).
This section starts with an explanation of how the questionnaire was designed and distributed. It is followed by the demographic analysis of respondents and data analysis techniques. The interviewing procedures, as well as the selection criteria of participants in the follow-up interviews, are discussed. The final section describes ethical considerations and possible limitations of the methodological design.

### 4.1 Questionnaire design

The online questionnaire consisted of 42 questions and was distributed in English, Russian, and Swedish, as these are the languages the author felt comfortable interviewing in. To take part in the questionnaire, the participant had to be a parent or a legal guardian of an autistic child and belong to a transnational family. The questionnaire had to be filled out by the child's primary or secondary caregiver. I divided it into three thematic sections.

Demographic information was elicited through eight questions, including three questions to determine the family's socioeconomic status (SES). The information about the child's diagnosis was asked in the three following questions. The question about additional
diagnoses was a multiple-choice item; it was based on DSM-5 (2013) diagnostic and statistical manual of mental disorders. Several questions were included specifically to trace the participant's migratory trajectories to "unpack the discursive reproduction" of the hierarchies of languages, gender roles, and intercultural encounters (Gomes, 2018). The latter is especially important, as people's intercultural encounters are closely intertwined with abyssal thinking (García et al., 2021; Santos, 2007), which incorporates not only racial hierarchies, but, in case of autistic people, the hierarchization of ableism that can be found in parental discourses and the recommendations they receive.

The first section also investigated the family's linguistic background. Twelve open-ended questions asked the participant which languages they use at home, outside the home, for watching TV, reading books, mobile apps, videogames, and boardgames. Based on the answers to these questions, two additional items used a five-point Likert scale to investigate the proficiency of the child in each language - both at home and outside the home. Two multiple-choice questions asked the participant what alternative communication the child uses at home and outside the home and in what languages. One multiple-choice question asked the participant to select all the educational organizations the child has either attended or is attending.
Section 2 investigated the family's attitudes and feelings about bilingualism. Five-point Likert scales (with 1 meaning strongly disagree, 5 - strongly agree) were used to elicit the participant's views about their autistic and neurotypical children's bilingualism. One question used a five-point Likert scale (with 1 meaning never, 5 - a great deal) to ask the respondent how much they are concerned about possible potential obstacles in their autistic child's bilingualism. This section also contained a question about whether the family had decided to raise their autistic child bilingually or monolingually. A multiplechoice question also elicited the participant to choose all the strategies used in their family if their autistic child is learning an additional language(s).

The final section used two multiple-choice items to ask about professional and casual advice given to families about their autistic child's bilingualism. Two open-ended questions asked the respondent to comment on the questionnaire and leave any suggestions or feedback on how to improve it. This section also asked the participant if they were willing to participate in an interview with the researcher and to leave their email address. I removed the email addresses from the data after contacting the participants.
Both sections 2 and 3 were modeled after the survey presented by Kay-Raining Bird et al. (2012) and adapted for a more diverse audience, not limited to the realities of anglophone countries. I was hoping that these design changes would help to challenge the predominance of replies from the WEIRD respondents. Thus, the questionnaire aimed to reach a wider audience with a broader range of lived experiences, not just those from the Global North and traditional families.

Some of the original questions about the child's diagnosis from the survey in Kay-Raining Bird et al. (2012) were also completely excluded or adapted, as the language used in that questionnaire was ableist and based on the DSM.IV.TR (Chao \& Manita, 2013) diagnostic and statistical manual of mental disorders. Thus, my question about additional
diagnoses was based on the most recent version of this manual - DSM-5 (2013), that does not include ASD diagnostic subcategories.

The questionnaire was pilot-tested by six people, including native and non-native speakers of English, autistic adults, autistic parents of autistic children, and neurotypical parents of autistic children. Pilot-runs of the questionnaire showed that it took approximately 15 minutes to finish. There were no compulsory questions, so the respondent could skip any question they wanted.

The questionnaire was hosted on SurveyMonkey© (1999-2022), a survey hosting platform that promotes the simple and clean design of questions, while providing opportunities to create a more advanced survey design. I tried to minimize the number of questions with free text answers, preferring the designs with checkboxes or multiplechoice answers. I sought to formulate the questions to be as simple as possible and keep the questionnaire as short as I could to avoid the respondent fatigue (Ruel et al., 2016). Despite that, I had to include additional sections to determine the amount of assistance each autistic child requires and cover all the additional modalities used within the family.

### 4.2 Procedure

Unlike prior questionnaires that targeted a specific pair of languages in intermarried couples (Roberts, 2021), immigrant families from a particular country (Oriyama, 2016), or a specific majority language (Slavkov, 2021), I tried to cover a larger potential target audience. One of the major advantages of having parental interviews at home is, of course, the possibility to conduct a fieldnote log, notice how many books and in what languages are present at a child's home, and even witness real-time interactions with the children. However, due to an ongoing COVID-19 pandemic, I decided to limit my qualitative research to online interviews. Suffice it to say, online interviewing has its advantages. You are no longer limited to one region; it is more sustainable, and people, in general, are more reluctant to invite a stranger into their homes. Anecdotal evidence from postrecording conversations with my participants suggests that many would not consider inviting a researcher into their homes.

The questionnaire was distributed in English, Russian, and Swedish via Facebook and Reddit. I targeted thematic Facebook groups for parents of autistic children, expat and immigrant groups in Sweden, and subreddits for families with autistic children. The majority of respondents came from the Facebook groups for Russian-speaking parents of autistic children in Sweden and Russian-speaking parents of autistic children living abroad.

Overall, the questionnaire was published in 11 Facebook groups, and two subreddits, and shared through my social media accounts in hope that my subscribers' reposts would lead to the so-called "snowball sampling" recruitment of potential participants. The questionnaire could be accessed through Survey Monkey; the responses were collected from November 2021 to February 2022 (inclusive).

I downloaded the data from Survey Monkey to a Microsoft Excel© file. The data was analyzed and visualized with Excel add-on software by Peltier Tech®.

### 4.3 Interviews

When preparing questions for the interviews and in their transcribing, I tried to address the main challenges of qualitative interviews (Potter \& Hepburn, 2012, pp. 555-557) that deal with the reporting of the interviews and their analysis.

The participants were recruited via the questionnaire about family language policies in families with bilingual autistic children. The main requirement for a participant was: they should be the main or secondary caretaker of a bilingual autistic child, or an autistic child who is exposed to a bilingual environment. Their child should have received the official diagnosis of ASD by the time of the interview or be in the process of receiving it. A selfdiagnosis was not included in the recruitment criteria. Since anecdotal evidence from pilot testing the questionnaire suggested that many parents of non-speaking autistic children do not consider them to be bilingual in comparison to both speaking autistic children, I clarified that parents of non-speaking autistic children qualify for both the questionnaire and the interview.

While the questionnaire mentioned only autistic children, I did not exclude parents of autistic adults from my recruitment criteria if they were diagnosed as children. Thus, the category "parent of an autistic person" was the central selection category for my interviews. The interviews were held and recorded only by me. I instructed the participants about the task before the interview. They were also supposed to read and sign the consent form or say the following phrase at the start of a recording: "Сегодня (ЧИСЛО). Меня зовут (ИМЯ), и я даю согласие на участие в этом интервью. Я понимаю, что могу остановиться и прекратить участие в интервью в любое время ${ }^{5}$."

I presented the participants with a chance to ask questions about the research at the end of the interview and they were provided with information regarding my future research plans. They were also offered a chance to read the transcripts of their interviews and make comments or suggestions about them. Full records are kept by the interviewer only; one transcript sample is included at the end of this thesis (see Appendix L), and the rest of the transcripts are accessible upon request.

I included not only the questions asked by the interviewer but also my comments and reactions in the interview transcripts. While I am not using the Jefferson transcription system (Jefferson, 2004) for this thesis, I used a verbatim transcription, including external noises, long pauses, ungrammatical sentences, short utterances, expressions of emotions, stuttering, and hesitations in the interview transcript.
I tried to avoid underanalysis through summary, taking sides, overquotation, isolated quotations, and overgeneralizing claims (Potter \& Hepburn, 2012, p. 560) when analyzing the interview data. The analytic observations of the interviews included awareness that

[^2]they might be "flooded with social science agenda" (Potter \& Hepburn, 2012, p. 556) and tried to avoid it.

Most of the questions were prepared before the interview, were open-ended, and based on the participant's replies to the questionnaire. However, as the participant revealed more information during the interviews, some questions were constructed spontaneously to clarify preceding replies or check the understanding of the previous question. Thus, the discursive organization of the interviews was semi-structured. The order of the questions was not strict but included a set of open-ended questions that the interviewer prepared beforehand and had to go through. Overall, I designed the interviews to "leave some room for sharing and negotiating world views" (Grindsted, 2005, p. 1017).

### 4.3.1 Coding of interviews

I analyzed the collected data from the interviews using descriptive and process coding (Charmaz, 2006; Saldaña, 2021). Codes could be described as short ideas explaining what is going on in the data. I conducted coding of all the interviews and used a simplified version of coding that included only open, axial, and selective codings (Charmaz, 2006; Delve, 2022).

In the open coding phase, I read the data line-by-line, where a line was conceptualized as a finished idea. This is the phase when a researcher is supposed to break the raw data into independent parts, sort the most frequent and significant initial codes and group them into larger chunks. The categories I used for such a segmentation were based on the participants' language practices, ideologies, management, as well as their views about autism.

In the axial coding phase, I drew connections between the categories from the open phase and organized them into larger categories. These large categories became the "axes" of all the established subcategories. While building those connections, I was also making memos, which are "written down connections between incidents, codes, properties, and categories" (Chametzky, 2016, p. 169).

The final phase, selective coding, combined all the thematic categories from the axial coding phase into a core category which is supposed to represent the central theory of a study. While working on the final phase, I built the participants' profiles as vignettes - a "rewarding way to share interview data" to "bring a participant alive, offer insights into the complexities of what the researcher is studying" (Seidman, 2006, p. 120).

### 4.4 Quality of the study

### 4.4.1 Ethical considerations

As already mentioned, the participants were asked to read and sign a consent form (Appendix B), which was created in accordance with EU General Data Protection Regulation 2016/679 (GDPR) and the Swedish Data Protection Authority
(Datainspektionen) and provided information about the study, how the data will be collected and stored, the participants' right to withdraw, and how to contact the researcher. Data was protected according to Stockholm University policies, and the participants' confidentiality was maintained. The participants could choose pseudonyms for themselves; those pseudonyms were used in the transcripts and the thesis. The data from the questionnaire and interview was only accessible to the researcher and her supervisor; the data will be stored on an external server for at least ten years after the findings are published. The participants received the finished transcripts and could offer suggestions or corrections; they were also reminded of their right to information and to withdraw from the study at any time.

### 4.4.2 Limitations

### 4.4.2.1 Participants

As I have already mentioned, most participants in the questionnaire were speakers of Russian as a minority language. This might be explained by my own identity and the fact that the Russian-speaking participants felt more inclined to help a fellow Russianspeaking researcher. Since I recruited the participants through social media, there is a possibility that such a method of recruitment might lead to having participants with higher SES. I tried to avoid this by using several languages to not limit this research to advanced English speakers and, in the end, this has led to a more diverse pool of respondents.

When it comes to interviews, the main limitation was that none of the interview participants' spouses or partners were present during the interviews. This limitation will be further addressed in the discussion session.

### 4.4.2.2 Data

One of the main limitations when it comes to quantitative data collection was that I could not clarify all the participants' replies, and as later suggested by the interview data, some questions could be misinterpreted by the participants. For example, the term "Key Word Signs" should have been further clarified within the questionnaire, as interview data suggests it was interpreted differently by each participant - either as "simplified" signing based on a sign language (correct interpretation), a set of "home gestures", or regular deictic gestures. Since I provided the questionnaire participants with an option to leave feedback, it helped me to draw an overall picture of its limitations. Thus, I should have clarified that a participant can fill in additional forms if they have several autistic children. One of the participants also had a feeling that the questions assumed the child's diagnosis was known at the time the language learning started - again, this should have been clarified in the questionnaire description; future researchers can also try to edit the questionnaire to examine whether the participant's FLP changed after receiving an official diagnosis. Despite these nuances, judging from the interview data, the majority of questions were not confusing and easy to interpret for the participants.

The main methodological limitation of this study is that it relies only on data obtained from the questionnaire and the participants' own reported accounts and experiences. Without any doubt, this research could benefit greatly if I had complemented it with field observations or video recordings of home interactions between the family members. However, due to time constraints, the narrow pool of participants located in Sweden, and health regulations during the COVID-19 pandemic, I decided not to investigate whether the participant's reported FLP matches their actual language use in real life.

### 4.4.2.3 Data collection and analysis

Since the interviews were conducted online and most participants were already familiar with this method of conversation due to their experience during the pandemic, I do not think there was a significant difference in how the participants acted during the interviews, had they been held offline. As the interviews were video recorded, it was easier for me to transcribe multimodal aspects of the interviews and create more reliable interview transcriptions.

### 4.4.2.4 Validity, reliability, and transferability

Qualitative coding helps a researcher to examine their data more systematically and increases the validity of the data analysis. Ideally, the data should be analyzed by several coders and then compared for intercoder reliability. However, due to the time limitations and the nature of this research being an MA thesis, the data was analyzed only by a single coder - me. I tried to follow all the achievable validity and reliability practices, such as practicing reflexivity, and negative case analysis (Delve, 2022). The former measure must have been practiced throughout the data analysis, as I am myself a member of a transnational family, am a white cis woman, and a mother of two children, including one autistic child. As a parent of an autistic child, I favor the neurodiversity paradigm, do not believe that vaccines cause autism, believe that autism is not a disease and, thus, cannot be cured, and consider myself to be an advocate for autism acceptance. I am also a supporter of LGBTQ+ rights and consider myself to be left-wing in terms of politics. These viewpoints are not shared by every member of the autistic community and parents of autistic children. All these facts could be influential in developing biased views and personal judgments about the participants who do not share the same worldview. It is important to remember that both the quantitative and qualitative components of this research are from the researcher's point of view, as I chose which questions to ask, and thus my positionality may have influenced both survey creation and interviews. As a researcher, I had to always keep that in mind when making assumptions and forming views about the participants and their FLPs during reflexivity. Such reflexivity was also linked to negative case analysis, which aids in recognizing alternative points of view and establishing the sources of such points of view, thereby making the research more reliable and robust (Delve, 2022).

## 5. Results

### 5.1 Questionnaire

Since none of the questions was mandatory, some participants skipped several questions. Out of 41 replies, one was excluded from the analysis since less than $10 \%$ of it was filled out. Sixteen questionnaires were filled in Russian, and 25 in English. One English version questionnaire was filled out in Swedish. No respondent used the Swedish version of the questionnaire. This could be partly explained by the hesitance of Swedish-speaking Facebook groups to publish the link to the questionnaire in the first place. Since most of the above-mentioned Facebook groups were private, the enrollment post with the research descriptions and the link to the questionnaire had to be moderator-approved first. None of the Swedish-speaking groups approved my posts, using the "self-advertisement/selfpromotion" group rules as the reason for declining the posts.

### 5.1.1 Demographics

The analysis included 40 surveys. Most of the surveys were filled out by mothers (see Table 1) and four respondents ( $10.26 \%$ ) were presumably single parents. All the presumably single parents were mothers.

Table 1. Participants' family status

|  | Caregiver 1 |  | Caregiver 2 |  |
| :--- | ---: | :--- | ---: | :---: |
| Mother | $37(92.50 \%)$ | Mother | $3(7.69 \%)$ |  |
| Father | $3(7.50 \%)$ | Father | $32(82.05 \%)$ |  |
| N/A | none | N/A | $4(10.26 \%)$ |  |

Out of 40 autistic children in this survey, 34 ( $87.18 \%$ ) were reported to be male, four ( $10.26 \%$ ) female, and one ( $2.56 \%$ ) non-binary. The mean age of the children was 9.0 (SD = 5.9). A majority of children are firstborn: $13(32.50 \%)$ are firstborn and have siblings, while 10 ( $25 \%$ ) are firstborn with no siblings. Eleven ( $27.50 \%$ ) children are second-born, and three $(7.50 \%$ ) children are third-born (or higher). Three respondents chose not to disclose this information. The majority of participants currently live in Sweden, Israel, and the UK (see Figure 1).


Figure 1. Participants' current countries of residence
Fourteen ( $67 \%$ ) children had moved countries at least once, five ( $24 \%$ ) children have relocated to another country twice or more, with only two ( $9 \%$ ) children living in the country of their birth (frequency missing $=7$ ). Half of the participants $(20,50 \%)$ were "extremely likely" to stay in their current country of residence, 11 (27.50\%) "likely" to stay, seven ( $17.50 \%$ ) unsure if they are going to stay, and two "unlikely" to stay.

### 5.1.2 SES

The survey participants were less reluctant to inform me about their current level of education, with the majority of caregivers $1(32,80 \%)$ and caregivers $2(26,72.2 \%)$ having a university level of education.

When it came to the economic part of SES, the picture was more diverse (see Figure 2). Overall, it can be presumed that many participants occupy high positions on the socioeconomic ladder. Whether higher SES has any correlation with earlier diagnoses of ASD is still debated, as data from the US studies show that people with higher SES have easier access to early diagnosis and higher quality of medical evaluations (Thomas et al., 2012), while data from countries with universal healthcare like Sweden contradicts these findings (Rai et al., 2012). Studies in developing nations showed that children from lower SES families are at greater risk of childhood autism (He et al., 2018).

While the participants from the survey come from different countries, some with universal healthcare, others without, single caretakers of autistic children from the survey (all mothers) occupied the four lowest income levels. This observation might be linked to the
findings that single and low SES mothers of autistic children experience the most negative impacts of decreasing paid work to manage autism services (Brewer, 2018).


Figure 2. Participants' reported incomes (in \%) indicate that many belong to the middle or uppermiddle class

### 5.1.3 Diagnosis

The primary diagnosis of children was ASD; the following additional diagnoses are summarized in Table 2.

Table 2. Additional diagnoses of participants' autistic children

| Diagnosis | Count | Percent |
| :--- | ---: | ---: |
| Intellectual Mental Disorder | 8 | 20 |
| Learning difficulties | 7 | 17.5 |
| ADHD | 12 | 30 |
| Motor impairment | 2 | 5 |
| Language disorders or speech delay | 23 | 57.5 |
| No specific diagnosis | 8 | 20 |
| Other | 3 | 7.5 |

As the "Other" additional diagnoses participants mentioned OCD and selective mutism. The mean age when the participants' children received an official diagnosis is reported to have been 4.2 ( $\mathrm{SD}=3.4$ ). Seven children are reported to be nonverbal $(17.5 \%)$, ten - to have a speech delay ( $25 \%$ ), and 22 were reported to be verbal ( $55 \%$ ). One participant chose "Other" $(2.5 \%)$ as a reply option, specifying "his speech is different, he speaks like a foreigner".

### 5.1.4 Language practices

Participants were asked to list up to six languages their autistic child is exposed to both at home and outside the home. Unlike Kay-Raining Bird et al. (2012), who only counted
spoken languages used at home and outside the home as "exposure to bilingualism", I also included unaided and aided low-tech and high-tech AAC, daily access to TV, media, books, apps, other gadgets, and entertainment platforms in more than one language as exposure to bilingualism. Thus, out of five participants ( $\mathrm{n}=40,12.5 \%$ ) who reported exposure to only one language at home (monolingual), only one child could be considered monolingual based on the above-mentioned criteria. While four other participants reported being monolingual at home, they were all exposed to more than two languages through means other than spoken language.

The participants reported all the languages that their family members use both at home and outside the home; the results indicate a clear prevalence of bilingual exposure (two or more languages) (see Figure 3).


Figure 3. Numbers of participants exposed to one, two, three, or more languages at home and outside the home

English (31\%), Russian (11.48\%), and Hebrew ( $9.84 \%$ ) were the top three most spoken languages in families with autistic children (see Figure 4). This is interesting, taking into account that only eight participants currently live in anglophone countries (see Figure 1).

home language

Figure 4. Most frequently reported home languages (in \%)
Based on the individual language use in each family, I created a summary of their FLPs (see Table 3). The MajL@H was usually practiced by families living in English-speaking countries, while ML@H was predominantly used by families where none of the parents is a fluent majority language speaker. Mixed language use was characteristic of intermarried families living in countries with a majority language other than the parents' first language or in intermarried families where one of the children decided to speak the majority language. Eighteen (45\%) autistic children share the same first language as their parents. Out of 22 children from intermarried families, 12 (30\%) share their mothers' first language, five ( $12 \%$ ) their fathers' first language, and five chose to speak a language different from their parents' first languages - presumably the majority language. Out of five families where the child's first language did not match their parents' first languages, four were using the Mixed Language Use FLP. However, these children's first languages also matched their main language of schooling. Thus, it is not clear what plays a more vital role; as the children spend a significant amount of time at school, it can be argued that the amount of language input received outside the home is greater than the amount of language input at home. OPOL was used in families where both parents have a high SES status, and one parent is a native speaker of the majority language. Such a result is not surprising, since this particular FLP is linked to prestige and WEIRD demographics.
Table 3. FLP used by participants $(\mathrm{n}=40)$

| FLP at Home | Frequency | Percent |
| :--- | :---: | :---: |
| Minority Language at Home (ML@H) | 17 | 42 |
| Mixed Language Use (MLU) | 14 | 34 |
| Majority Language at Home (MajL@H) | 7 | 17 |
| One Parent - One Language (OPOL) | 3 | 7 |

The questionnaire also investigated family language practices like watching TV and streaming platforms (e.g., Netflix, Disney+), reading books, using mobile apps, and playing videogames and boardgames. The results show that the majority of children consume digital content in multiple languages (see Figure 5). One participant (3\%) is not allowed to watch any TV content. Children who have screen time in one language are predominantly exposed to the majority language. However, the "analog" hobbies like reading and boardgames show a different picture. An equal number of participants reported reading books in one language $(18,47.5 \%)$ and multiple languages $(18,47.5 \%)$. The majority of participants ( $19,54 \%$ ) seemed to prefer playing boardgames in one language, with only five ( $14 \%$ ) playing them in multiple languages and 11 ( $32 \%$ ) not playing any at all. Overall, the preference for multilingualism when it comes to digital resources and screen time was more obvious than for "analog" ones (books, boardgames).


Figure 5. The number of participants exposed to languages at home through means other than family members

### 5.1.4.1 Language proficiency

The participants were also asked to evaluate their autistic children's abilities to understand and communicate in each language used at home using a five-point Likert scale $(1=$ "more than age-appropriate", $2=$ "age-appropriate", $3=$ "less than ageappropriate", $4=$ "much less than age-appropriate", $5=$ "not at all"). Similar to KayRaining Bird et al. (2012), I decided to compare language skills in the participants’ reported first language. Language skills for the reported first languages of both monoand bilingual autistic children were similar, and the reported first language skills for
bilingual children were not lower than their skills in their second reported language. The reported ratings for the first language of the children are presented in Table 4.

Table 4. Number of respondents (and \%) and their ratings of their autistic children's reported skills in their dominant language, raised in reportedly monolingual $(n=5)$ and bilingual $(n=35)$ families

|  | more than <br> age- <br> appropriate | age- <br> appropriate | less than <br> age- <br> appropriate | much less <br> than age- <br> appropriate | not at <br> all | Missing <br> freq. |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Monolingual |  |  |  |  |  |  |
| Comprehension | $1(20 \%)$ | $2(40 \%)$ | $1(20 \%)$ | $1(20 \%)$ | $0(0 \%)$ | $0(0 \%)$ |
| Communication | $1(20 \%)$ | $1(20 \%)$ | $0(0 \%)$ | $1(20 \%)$ | $0(0 \%)$ | $2(40 \%)$ |
|  |  |  |  |  |  |  |
| Bilingual |  |  |  |  |  |  |
| Comprehension | $8(23 \%)$ | $8(24 \%)$ | $14(41 \%)$ | $4(12 \%)$ | $0(0 \%)$ | $0(0 \%)$ |
| Communication | $3(9 \%)$ | $1(3 \%)$ | $4(12 \%)$ | $1(3 \%)$ | $3(9 \%)$ | $22(64 \%)$ |
| Non-speaking |  |  |  |  |  |  |
| Comprehension <br> Communication | $0(0 \%)$ | $1(16 \%)$ | $4(67 \%)$ | $1(17 \%)$ | $0(0 \%)$ | $0(0 \%)$ |

I did not include reading and writing in language skills, which could be identified as a potential limitation for the data interpretation in this study. However, this sacrifice was done to limit the amount of time spent on the survey, since the pilot test showed a high abandonment rate for questions about language and literacy abilities. It can be seen from the data (see Table 5) that many respondents skipped the question about communication skills. These survey design limitations could be investigated further to develop a less "tiresome" survey design.

Table 5. Means (and standard deviations) of reported comprehension and communication skills for every language used within both monolingual $(\mathbf{n}=5)$ and bilingual $(\mathrm{n}=35)$ families, as well as nonspeaking $(\mathbf{n}=6)$ and speaking/minimally speaking $(\mathrm{n}=34)$ autistic children

|  | Language 1 | Language 2 | Language 3 | Language 4 | Language 5 |
| :--- | :--- | :--- | :--- | :--- | :--- |
| Monolingual |  |  |  |  |  |
| Comprehension <br> Communication | $2.4(1.1)$ |  |  |  |  |
| Bilingual |  |  |  |  |  |
| Comprehension | $2.3(0.9)$ | $3.2(0.8)$ | $3.5(0.9)$ | $3.6(1.1)$ | $4(0)$ |
| Communication | $2.9(1.5)$ | $3.4(1.2)$ | $4.8(0.4)$ | $5(0)$ |  |
|  |  |  |  |  |  |
| Non-Speaking | $3.1(0.9)$ |  |  |  |  |
| Comprehension | $4.7(0.4)$ |  |  |  |  |
| Communication |  |  |  |  |  |
|  |  |  |  |  |  |
| Speaking | $2.2(0.9)$ |  |  |  |  |
| Comprehension |  |  |  |  |  |
| Communication | $2.1(1.0)$ |  |  |  |  |


| All participants |  |
| :--- | :--- |
| Comprehension | $2.4(1.0)$ |
| Communication | $3.5(1.4)$ |

All participants
Comprehension
3.5 (1.4)

Independent $t$-tests showed that parents perceived that autistic children raised in monolingual and bilingual families showed no difference in their dominant language comprehension $\left(\mathrm{M}_{\text {monolingual }}=2.4, \mathrm{SD}=1.1 ; \mathrm{M}_{\text {multilingual }}=2.3, \mathrm{SD}=0.9 ; t(38)=0.226 ; p\right.$ $=0.822$ ) and communication ( $\mathrm{M}_{\text {monolingual }}=2.3, \mathrm{SD}=1.5 ; \mathrm{M}_{\text {multilingual }}=2.9, \mathrm{SD}=1.5$; $t(38)=0.836 ; p=0.408)$. However, as already mentioned, only one participant could realistically be treated as strictly monolingual. This participant was one of the youngest and had just received their diagnosis, so they might experience more input in additional languages in the future from digital contents. Unlike Kay-Raining Bird et al. (2012), who only compared autistic children raised monolingually and multilingually, I also ran independent $t$-tests on speaking and non-speaking autistic children. Predictably, the test showed statistical significance for comprehension ( $\mathrm{M}_{\text {non-speaking }}=3.1, \mathrm{SD}=0.9 ; \mathrm{M}_{\text {speaking }}$ $=2.2, \mathrm{SD}=0.9 ; t(38)=2.258 ; p=0.029)$ and an extreme significance for communication $\left(\mathrm{M}_{\text {non-speaking }}=4.7, \mathrm{SD}=0.4 ; \mathrm{M}_{\text {speaking }}=2.1, \mathrm{SD}=1.0 ; t(38)=6.225 ; p<0.0001\right)$. However, two out of six participants with non-speaking autistic children mentioned in their open answers that their children's alternative communication skills using visual and/or gestural modalities are age-appropriate or less than age-appropriate. This data suggests that further investigation is needed to differentiate more between perceived communication skills in spoken and other modalities.

Overall, 17 participants raising autistic children bilingually ( $\mathrm{n}=35$ ) reported that their children's first language comprehension skills are better than all the additional languages, 17 reported them to be the same, and only one participant reported it to be worse than the second language. When it comes to communication skills ( $\mathrm{n}=14$ ), five respondents claimed that their children's first language communication skills are better than in the second language, four believed that the children communicate in both languages equally well, and four - to have no spoken language skills.

### 5.1.4.2 Language practices outside the home

In the part about language exposure outside the home, only four (10\%) respondents ( $\mathrm{n}=$ 40) stated that their autistic children were exposed to only one language outside the home, $17(42 \%)$ were exposed to two languages, and $19(48 \%)$ to three or more. Participants who reported exposure to only one language are all from the EU. Most of the respondents who named only two languages outside the home are from English-speaking countries. The majority of reported language exposure outside the home happened at kindergartens, schools, through relatives, healthcare providers, personal educational assistants, and heritage language classes. Three respondents mentioned in their open-ended replies that their children were exposed to "all languages", attributing it to living in diverse neighborhoods. Not surprisingly, English is mentioned by 33 ( $82 \%$ ) participants as one of the languages outside the home. Children who are not exposed to English are too young
to be exposed to it through education and come from countries like Poland ( $\mathrm{n}=1$ ), Israel ( $\mathrm{n}=3$ ), and Germany ( $\mathrm{n}=2$ ).

Out of 18 participants who answered that their autistic children had attended educational organizations in their previous countries of residence, 14 (78\%) were educated in a monolingual environment, and only four ( $22 \%$ ) in a multilingual one. This ratio did not change dramatically after the participants' move to their current country of residence: 23 (68\%) participants attended monolingual educational settings, and 11 (32\%) multilingual.

### 5.1.4.3 Alternative communication practices

The respondents could select all the applicable methods of alternative communication currently used with their autistic child. The participants' selections are summarized in Table 6. They were also asked to indicate if any of the alternative communications were linked to a named language, as some AAC methods use only visual modalities. Seven ( $70 \%$ ) respondents were using alternative communication at home in two languages, and three (30\%) in one language. Open-ended replies also mentioned using printed communication charts, typing on the phone, and Makaton. Some open-ended replies indicate attempts to introduce alternative communication that were given up as soon as the child started speaking. Most of the alternative communication devices and tools used English, Russian, and Swedish. This could be partially explained by the lack of languages offered by most manufacturers of AAC, as well as parental attitudes towards alternative communication, and access to alternative communication devices.

Table 6. Alternative communication used in families with autistic children at home

|  | Count | Percent |
| :--- | :---: | :---: |
| None of the above | 19 | 47.5 |
| Key Word Signs | 10 | 25 |
| Visual schedules | 8 | 20 |
| PECS | 6 | 15 |
| Sign language ${ }^{6}$ | 4 | 10 |
| High-tech aided systems $_{\text {Communication apps }}$ | 3 | 7.5 |
| Other (please specify) | 2 | 5 |

30 participants also reported that their autistic children used alternative communication outside the home (see Table 7). All but two participants ( $8,80 \%$ ) used alternative communication outside the home in one language. Out of these eight participants, only one ( $13 \%$ ) used the minority language for alternative communication outside the home. Based on the comments to this question, it could be concluded that the majority of schools

[^3]do not provide bilingual support when it comes to alternative communication and were focused on the majority language-only. Only one participant commented that the school tried to use bilingual AAC (English and Spanish) with their autistic non-speaking child.

Table 7. Alternative communication used outside the home

|  | Count | Percent |
| :--- | :---: | :---: |
| None of the above | 23 | 57.5 |
| Key Word Signs | 8 | 20 |
| Visual schedules | 7 | 17.5 |
| PECS | 5 | 12.5 |
| Communication apps | 3 | 7.5 |
| Other (please specify) | 3 | 7.5 |
| Sign language | 2 | 5 |
| High-tech aided systems | 2 | 5 |

### 5.1.5 Parental views about bilingualism

The third part of the questionnaire investigated the participants' language beliefs in relation to their autistic children and non-autistic children (if they have any). The participants were asked to evaluate their attitudes towards two statements: "It is important for my child with ASD to be bilingual" and "It is important for my child(ren) without ASD to be bilingual". The evaluation used a five-point Likert scale ( $1=$ "strongly disagree", $2=$ "disagree", $3=$ "neither agree or disagree", $4=$ "agree", $5=$ "strongly agree"). Replies are presented in Table 8.

Table 8. Participants' evaluations of the statement "It is important for my $\qquad$ child to be bilingual" show a preference for bilingualism in non-autistic children

|  | Autistic |  | Non-autistic |  |
| :--- | :---: | :---: | :---: | :---: |
|  | Frequency | Percent | Frequency | Percent |
| Strongly agree | 17 | 44.74 | 17 | 62.96 |
| Agree | 3 | 7.89 | 8 | 2.63 |
| Neither agree or disagree | 16 | 42.11 | 2 | 7.41 |
| Disagree | 1 | 2.63 | 0 | 0.00 |
| Strongly disagree | 1 | 2.63 | 0 | 0.00 |
|  | Frequency Missing $=2$ | Frequency Missing $=13$ |  |  |

After comparing evaluations for both statements in families with autistic and non-autistic children ( $\mathrm{n}=27$ ), independent $t$-tests showed a very statistically significant difference $\left(\mathrm{M}_{\text {autistic }}=4.0, \mathrm{SD}=1.1 ; \mathrm{M}_{\text {non-autistic }}=4.4, \mathrm{SD}=0.6 ; t(26)=2.801 ; p=0.009\right)$ indicating a preference for bilingualism for non-autistic siblings. The participants were also asked to evaluate their agreement with the statements that bilingualism can improve the following areas of life: "communication with family members", "communication with people in your country of residence", "communication in school/kindergarten", "life opportunities", and "future employment". The evaluation used a five-point Likert scale
( $1=$ "strongly disagree", 2 = "disagree", $3="$ neither agree or disagree", $4=$ "agree", $5=$ "strongly agree"). Paired $t$-tests and Wilcoxon Signed Rank tests (non-parametric median tests) performed for families with both autistic and non-autistic children showed no statistical difference among participants. However, when comparing non-autistic children and non-speaking autistic children, an independent $t$-test revealed a statistical significance for the statements "bilingualism improves communication with family members" ( $\mathrm{M}_{\text {non- }}$ speaking $\left.=3.0, \mathrm{SD}=0.0 ; \mathrm{M}_{\text {non-autistic }}=2.6, \mathrm{SD}=0.5 ; t(14)=2.262 ; p=0.0401\right)$ and a strong statistical significance for "bilingualism improves future employment" ( $\mathrm{M}_{\text {non-speaking }}=2.8$, $\left.\mathrm{SD}=0.3 ; \mathrm{M}_{\text {non-autistic }}=1.7, \mathrm{SD}=0.7 ; t(14)=4.047 ; p=0.0012\right)$. Other statements revealed no statistical significance.

Participants were also asked about concerns they have felt about any potential obstacles regarding additional language learning by their autistic children using a five-point Likert scale $(1=$ "a great deal", $2=$ "a moderate amount", $3=$ "occasionally", $4=$ "rarely", $5=$ "never"). The participants were supposed to evaluate the following statements: "learning an additional languages is too hard for my child", "there is not enough professional help for my child", "I cannot help my child learn another language", "I am afraid my child will become less fluent in their native languages", "I am afraid my child will become confused by two/more languages", "I do not have access to services that can help my child with bi/multilingualism", "my family and/or friends will not support my decision", and "I am not sure if it is better to focus on one language". Replies (see Figure 6) indicate that the participants worried the most about the amount of professional help and access to it, rather than potential obstacles often associated with additional language learning among autistic children (Kay-Raining Bird et al., 2012). When comparing individual replies of parents with non-speaking children, the results indicate that parents of non-speaking children were even more worried about the amount of professional help and access to services than parents of speaking autistic children.


Figure 6. Replies to the question "Have any of the following potential obstacles concerned you in regard to your child with ASD and learning other languages?"

Open-ended replies also show how conflicted some respondents felt about their decisions about language and prioritizing their children's overall development over language planning:

> I have been given a guilty feeling about not prioritizing Russian, no help provided - parents on their own. However, I do not have Russian surroundings in my life and no possibilities to practice Russian either than at home. But we have had other issues with my son's development, which we had to prioritize instead of pushing Russian language understanding [sic].

Overall, it can be argued that many potential issues associated with bilingualism in autistic children are more related to the amount of support their parents wish to receive.

### 5.1.5 Language management

Thirty-two ( $84 \%$ ) respondents decided for their autistic child to speak two or more languages, three $(8 \%)$ - to speak the majority language of their current country of residence, two (5\%) to speak their native (ML@H) language, and one (3\%) had not decided yet. The participants were also asked to select every language learning strategy they were currently using or had previously used to promote language learning; they could select multiple answers (see Table 9).

Table 9. Language management strategies used by families with autistic children who learn additional language(s)

|  | Count | Percent |
| :--- | :---: | :---: |
| My child has a language tutor | 4 | 4.00 |
| My child takes special language classes | 3 | 3.00 |
| My child receives bilingual speech pathology support | 6 | 6.00 |
| We teach the additional language(s) at home by ourselves | 9 | 9.00 |
| We speak our native language(s) at home but outside of the home - we | 10 | 10.00 |
| speak another language(s) |  |  |
| My child attends school/kindergarten in a second/another language(s) | 21 | 20.00 |
| My child watches TV in both native and additional language(s) | 17 | 17.00 |
| My child watches TV only in their native language(s) | 2 | 2.00 |
| We read books in both native and additional language(s) | 21 | 20.00 |
| We read books only in a second/additional language(s) | 1 | 1.00 |
| We read books only in our child's native language(s) | 5 | 5.00 |
| Other (please specify) | 3 | 3.00 |

In general, the participants delegated a lot of responsibilities linked to bilingualism to educational organizations and providers and preferred tactics that are supportive of bilingualism. Open-ended replies indicated that some parents were having issues with motivating their teenage autistic children to read in any language; others pointed out that they preferred to focus on speech therapy in the minority language.

Many practitioners had not provided families with autistic children with any advice concerning the family's bilingualism ( $51,31 \%$ ). The second most-often given advice to the parents of bilingual autistic children was to raise their children bilingually ( $37,23 \%$ ). Twenty-two ( $14 \%$ ) specialists advised the parents to focus on the language of their current country of residence, $21(13 \%)$ to use OPOL, $16(10 \%)$ suggested the parents to use different languages in different places (e.g., MajL at school, native language at home), and $15(9 \%)$ advised focusing on the child's native language. Several open-ended replies also indicated that some specialists continued advising people to focus on just one language:

> Many of the so-called "specialists" we went to for help with speech recovery were very much advising us to give up multilingualism and focus on just one language. They justified it by saying that more than one language is very difficult [sic].

After an individual analysis of each participant's replies, it is also evident that despite an increase in advice favoring bilingualism, the majority ( $22,65 \%$ ) of families continued to receive contradictory advice from health and education practitioners, with only 12 (35\%) families receiving uniform advice from specialists about their autistic children's bilingualism. Autistic children that could be characterized as emergent bilinguals in their majority language tended to receive advice favoring monolingualism (with no clear preference for majority or minority language); however, racialized emergent bilinguals received advice in favor of the majority language. Additional individual analysis of recommendations given to the families of non-speaking autistic children revealed an interesting trend: educational professionals tended to give advice favoring monolingualism and the majority language, in particular, while healthcare professionals favored bilingualism.
Even more contradictory advice was received from other sources like social media, online forums, relatives, friends, and news media. It is unclear from the quantitative data alone how families with autistic children navigate within the sea of so much contradictory advice.

### 5.2 Interviews

Out of 41 respondents to the questionnaire, 18 chose the "agree" option in the question about the potential interview. I contacted all the participants who agreed; nine participants replied and booked an interview with me. I interviewed nine participants remotely, over Zoom and FaceTime (see Table 10). The participants had a choice to either have a single long interview or split it into two short ones. Everyone decided to have single interviews. All but one interview was held in Russian. The interviews lasted between 40 and 60 minutes. One interview (with Isabella) was held in English.

Table 10. Interviewed participants

| Participant | Country of residence | Age | Diagnosis | Home language | FLP@Home | Language of schooling |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Roman | North America | 6 | ASD; learning difficulties; motor impairment; speech delay | English, Russian | MajL@H | English |
| Anton | Germany | 2 | $\mathrm{ASD}^{8}$; speech delay | Russian; <br> Arabic; <br> English; <br> German; <br> Armenian | OPOL | N/A |
| Mats | Sweden | 6 | ASD; intellectual mental disorder; speech delay | Swedish; <br> Russian | OPOL | Swedish |
| Nikita | Spain | 13 | ASD; learning difficulties; speech delay | Russian | ML@ ${ }^{\text {H }}$ | Castilian, Valencian |
| Ilya | Israel | 7 | ASD; ADHD; ODD | Russian, <br> Hebrew | MLU | Hebrew, Russian |
| Robert | Sweden | 9 | ASD; speech delay | Russian, Spanish | OPOL | Swedish |
| Fredrik ${ }^{9}$ | Sweden | 36 | Asperger's Syndrome | English; Swedish | MajL@H | Swedish, English |
| Mark | Sweden | 10 | ASD; intellectual mental disorder; learning difficulties; speech delay | Russian, <br> PECS <br> (Ru+Swe), <br> High-tech <br> AAC (Swe) | ML@ ${ }^{\text {H }}$ | Swedish, <br> AAC <br> (Swe), <br> PECS <br> (Swe) |
| Artem | Lebanon | 9 | ASD; speech delay | Russian, French, Arabic | MLU | French, Arabic |

[^4]
### 5.2.1 Liana and Roman

Liana and her adopted six-year-old son Roman live in an English-speaking country. Liana is originally from Russia and moved to her current country of residence in the early '00s. She is part of an Indigenous population in Russia and, as a result, was raised bilingually in Tatar and Russian, although she believes Russian to be her dominant language. Liana spoke only Tatar before starting school, then in school, she was only exposed to Russian. As a result, as Liana remembers it, she "forgot Russian" during summer vacations spent at her grandmother's and in September - when children in Russia return to school - she "forgot Tatar and spoke in Russian" until eventually she "only spoke Russian". Thus, Liana personally experienced subtractive bilingualism that led to a loss of Tatar as her dominant language. I can only speculate to what extent her own experience has influenced her views about bilingualism, but it is obvious that Liana does not see bilingualism as a disadvantage.

Liana adopted Roman from Eastern Europe when he was 3.5 years old. According to her, by that time he could say roughly 16 words in his native language and had not received an official diagnosis yet. When it comes to autism and its intersectionality with class, it is important to mention that Liana belongs to the middle class and lives in a country with universal healthcare, thus, she generally praised the amount of support Roman receives through healthcare and education. She only complained about the time it took them to get an official diagnosis to access these resources.

Unfortunately, Liana encountered some prejudice and covert racism in her current country of residence as a woman of color who has just adopted a child of a different race. She recalls her experience in looking for language support from Roman's school:
> (Q: To what extent do you think your child's school supports your son's bilingualism?)
> Bilingualism? They don't support it. I think at first everyone probably thought that he didn't speak just because he didn't know English. And I had to, I don't know, for a year there, I was kind of fighting with everybody and proving that he didn't speak not because he didn't know English, but that he didn't know, didn't speak any language. Because if he spoke [Roman's first language], let's say, he would talk to everybody in [Roman's first language]. But he didn't. And it was important to them what language I spoke. At home. So, they thought he didn't know English. That's why he doesn't speak. And for them, they just wanted me to speak English.

Thus, Liana had experienced some "racialized micro-aggressions" (Block \& Corona, 2019; Fleras, 2016) and was treated as a racialized bilingual by her son's school in the beginning. While she lives in an officially bilingual country and belongs to the middle class, she was denied legitimacy as a speaker of two dominant and prestigious societal languages. She was also covertly judged by her interlocutors for the lack of exposure to the majority language at home who concluded that it was the main reason for Roman's "poor" competency in English. Here covert racial profiling resulted in a slower granting of access to resources for an autistic child. This access to autism resources was granted
later by Roman's third speech therapist who "already understands that we have not just arrived".

It is not clear to what extent these experiences or the fact that Liana and Roman do not share the same first language have formed Liana's language ideology and shaped her practices. However, despite her positive beliefs about bilingualism and that autism is not a barrier in becoming bilingual as "they (autistic people) have more potential than we all think" - Liana decided to focus on English only as their home language. In her eyes, English has the highest value, as she puts it - "I want him to learn English. So that everyone can communicate with him. Not only my family".
Before his move to North America, Roman used to watch YouTube videos in English, so he was familiar with English and had started learning it quickly. He was able to say his first sentence after eight months since his arrival to his new country. Liana says that she uses "very simple English" with him, to make the language input more understandable. Overall, the dominant home language in their family is English, but Roman can also hear Liana speaking Russian and Tatar with her parents over video calls. Roman has not been to Russia yet because of the COVID-19 pandemic, but he participates in Liana's video calls with her parents. Liana is anticipating future visits to Russia after the pandemic and believes that "they'll teach him Russian" when referring to her family.

Liana and Roman use educational apps in English on the iPad, and Liana has decided that Roman will learn and speak English only. She is, however, open to the possibilities of him learning other languages in the future, especially his heritage language. In assessing Roman's language development, Liana jokingly mentioned that Roman "will be able to survive" with his current level of speech development. She also believes that Roman can adjust his language to his interlocutor's and distinguishes different languages:
(Q: How do you see the relative advantages or disadvantages of living in a bilingual home for autistic children?) I think there are. He already understands that. Because he distinguishes between Russian and English. He knows who I speak Russian to, who I speak English to. He tries to say "hello" to Russian speakers in Russian. So, he kind of separates it. That is, his brain perceives it in some way. He reacts, and he's interested.

This description contradicts her later observation that Roman "doesn't perceive languages" because he does not show preference for any language when watching video content in "all of them" and does not distinguish between different scripts on public street signs.

It is worth mentioning that even though Liana considered introducing French as a second majority language into Roman's language repertoire, she was hesitant about it and believes that it is only for people who are "from France". She provided more detailed information about her language ideologies when discussing Roman's future by linking knowledge of English to prestige. She pointed out that if Roman learns how to speak English - "he'll have a lot of job opportunities" and can go "to any country".

### 5.2.2 Rita and Anton

Rita and her husband live together with their autistic son Anton and his two older neurotypical sisters in Germany. Rita is Armenian but lived most of her life in Russia. Her husband is from Syria. Their family uses at least five languages at home: Russian, Arabic, English, German, and Armenian. Rita speaks Russian with her children and English with her husband. Her husband speaks Arabic to their children. Rita notes that Armenian holds a special place in her language repertoire: it is her "secret language" that is "nothing on the scale of the planet" but she can use it to "talk about anything". She believes that bilingualism is a crucial part of their family, and "is not a hindrance". Rita was also raised bilingually in Russian and Armenian; she does not regard bilingualism to be an obstacle or linked to her son's speech delay when answering my question about her motivation for raising her son bilingually:

> And I know that bilingualism is not the cause of speech delay as many people think. That it depends individually on the child, on the person. So, it's important for him to be, not even bilingual, because it's important for him to know both Russian and Arabic in order to communicate with his relatives. And to know German because we live here. And I don't think that bilingualism in our family was the reason that he doesn't speak.

Anton is two and a half years old; he has a speech delay and is currently in the process of receiving an official diagnosis. According to Rita, he understands three languages: Russian, Arabic, and Armenian. Her son has not started attending German kindergarten yet, so the family believes that Anton will learn German when he starts schooling. The family uses the OPOL method with their children and believes that it's better not to use ungrammatical German around children; Rita's comment - "speak the language you speak" - sums up the family ideology about their family language. Even though both Rita and her husband speak German, they use English between themselves. Anton's neurotypical sisters use Russian, Armenian and Arabic at home and are balanced simultaneous bilinguals in Russian and Arabic (they started learning languages at the same time and are equally proficient in both). They have also added German to their repertoire at school.

Rita plans to raise Anton bilingually in Russian, Arabic, and German. The family decided not to watch TV in the presence of Anton, as Rita believes that Anton loses interest and motivation in everything while watching cartoons:

> I know that using gadgets and TV is both not helpful and not harmful to these kids. But I have noticed a tendency that if he watches something on TV, he withdraws into himself. If there's no TV, he's interested in us. He interacts with us. That's why I acted so harsh and turned everything off (laughing).

However, she admits that it's almost unrealistic to apply the same rules to her daughters. As a result, Anton might accidentally see some video content when his sisters are watching TV. Here one can see a clear example of abyssal thinking in language management based on the diagnosis: the neurotypical children get access to digital
content, while their autistic sibling does not. Rita admits that this parental gatekeeping of screen time is caused by Anton's language development.

Despite different policies towards screen time, Rita sees many advantages to her son's bilingualism:
(Q: What do you see as the advantage of having a child growing up in a bilingual environment?) The advantage is that he has more opportunities for communication. That is, there are no difficulties when communicating with people of different nationalities. I'm not saying that we cover everyone, but at least we avoid these difficulties. We do not need an interpreter.

Rita's positive views about bilingualism are especially noticeable when she narrates her experience in encountering professional advice to focus on one language at home for her autistic son:
(Q: How do you feel about these expert views?) I don't see the point. Honestly. I mean, how can I focus on one language if we have such a... Multilingual environment. Isolate him from his dad? Not letting him speak? That's not gonna work.

As a result of hearing advice that was not favoring bilingualism and OPOL, Rita decided to change their healthcare specialist. However, Rita decided to look for another practitioner not because of the language ideology of the previous pediatrician, but because they were not giving her son a referral to see a neurologist, thus not granting them access to an official diagnosis and the redistribution that usually follows it:

But when the pediatrician said - "I will not give you a referral to a neurologist, because your child is not calm and does not let me examine him". Yeah. That seemed a little weird. I changed the pediatrician and said the only thing I want is advice, tell me, help me. I'm not expecting any miracle. That's the kind of support I need, understanding. And not to put a label on the child.

Rita was searching for recognition of this issue, which was not granted by her son's previous pediatrician. She used her opportunity to change the health practitioner that is provided by the universal multi-payer health care system in Germany. Because Rita and her family belong to the lower-middle class, she's dependent on the resources and help provided by the government in terms of both healthcare and education for her son. She even admitted that she would prioritize waiting "to hear back from the health department about a special daycare" for Anton over having an opportunity to visit her family in Russia:

That is, if there is a choice between visiting parents and a kindergarten, I naturally choose kindergarten. Because it's important for me to put him, like, develop him and make him normal. I'm really hoping for that. Because the potential is there. It's not the most difficult case.

Here Rita speaks not only about the priority of redistribution over an opportunity to see her loved ones, but she also voices her hopes to "make" Anton "normal". Such abyssal thinking often results in a common belief among parents of newly diagnosed autistic children that there is a "normal" child in the shell of their child (Fletcher-Watson \&

Happé, 2019). This ableist abyssal thinking was voiced again when I asked Rita about her plans for her son's future in terms of language and education:

I don't have grand plans. I want him to talk. I want him to be the most ordinary child. The most banal, the most common, the most ordinary, no different from the ordinary people. (laughing) That's my, that's my goal for now. Yes (laughing).

It is important to mention that Anton is only two years old and can significantly benefit from early help in education and healthcare (Fletcher-Watson \& Happé, 2019). Thus, Rita's concerns that they're losing precious time while waiting for an official diagnosis are understandable. Like many parents from the lower-middle class, her access to resources depends on official recognition of her son's diagnosis. She highlights that in Germany "it takes a very, very, very long time". As a result, Rita hopes that as soon as Anton develops speech, learning any additional languages will not cause him any trouble. She concludes that "if a person speaks, he can speak all languages". Rita admits that she is only concerned with Anton's development as bilingualism "has never been an issue".

### 5.2.3 Alina and Mats

Alina, her husband Gustav, and their 6-year-old autistic son Mats live in Sweden. Alina is originally from Russia but moved to Sweden when she was 13. Gustav's mother is Swedish; his father is Greek. However, he was raised mostly in Swedish. They speak Swedish to each other but use OPOL with their son. Alina's mother also lives in Sweden, and Mats is exposed to Russian through her as well. His Swedish-Greek grandparents live in another country; their mobility and communication with Mats have been greatly influenced by the pandemic and mostly happen online these days.
Mats is autistic and has psychological and speech delay. He was completely non-speaking until the age of four and still requires a significant amount of help in communication. Alina points out that she and her husband both played an equal role in decision-making when it comes to using both their languages around Mats. She believes that her husband has a lot of regrets about not being equally proficient in his father's native language and wanted to do everything he could to make Mats a balanced bilingual. Despite being a sequential bilingual herself, Alina also believes that bilingualism is "when you grow up with two languages since birth". She has decided that her children would be raised bilingually even before her son's birth:

> (Q: You decided that he would learn and speak two or more languages. Can you tell us more about these decisions? What motivated you?) I decided for myself that my baby would speak several languages before having him (laughing). Because. Learning languages is in many ways a very important thing, not only for general development, but also for, for functioning in the modern world. And there are also many scientific studies about that, that bilinguals in many ways have a better brain function than those who know only one language from childhood.

Alina admits that she has considered whether the "burden" of learning additional languages "with all the diagnoses" was "too great" for her son. She remembers how her decisions were questioned by her in-laws who asked if bilingualism is "giving the child
an additional disability". To address these concerns Alina and her husband conducted a thorough research of scientific publications on the effects of bilingualism on autistic children:

> (Q: What do you think are the main difficulties or positive aspects of raising an autistic child bilingually?) We certainly thought about it. But we started reading different studies, scouring different websites about autism. What the advice was. Turns out that bilingualism for young autistic people is a good thing, too. There are scientific studies about it. Which made us happy. And besides, we decided it was probably too late to change languages, because our boy is a creature of habit, like all autistic people.

Alina believes that OPOL is a very effective approach and shares a story about her experiment with Mats: she tried to speak to him in Swedish when he was one year old; Mats "got terribly offended" and did not want to talk to her. Thus, we can see that according to Alina, Mats attributed Russian as his mother's language, and Swedish as his father's before he started speaking. Alina also compared her family's success in implementing OPOL with other families in a comparable situation:

> (Q: How much do you agree with this approach (OPOL)?) I agree $100 \%$ because I've seen a lot, I've seen a lot of examples around me in mixed families. That when parents don't follow this rule and mix languages. That the child ends up learning just one language and doesn't want to speak the other language. The language of mom or dad, which is not the main language in society.

Alina and her husband also use OPOL in reading; they try to buy the same books in Russian and Swedish and read them to Mats. However, Alina admits that she does most of the reading. Mats also watches cartoons in different languages, including English.
Alina is worried that Mats is more proficient in Russian and speaks little Swedish to his father; he also does not speak any Swedish at kindergarten. The teachers at kindergarten use PECS in Swedish to communicate with Mats. Mats also learned to reply in PECS in Swedish at kindergarten. The family also tried introducing PECS when Mats was nonspeaking to "shake up his speech", however, they stopped using it as soon as Mats started saying his first words.
Alina believes that a lot of Mats' frustrations come from his difficulties to articulate what he wants to say. The family has noticed significant progress in Mats' communication once he started kindergarten. Alina believes that Mats would make even more progress if they could receive more support from their speech therapist at the Autism Centre who "do a really good job there, but it's too rare". Alina shares her mild frustration with the amount of received support since she believes that developing speech is "the most important thing". Her dissatisfaction with the amount of local redistribution of resources in speech therapy led her to alternative solutions. Thus, they were considering visiting specialists in St. Petersburg or Moscow before the pandemic - a practice many families with ties to post-Soviet countries do.
When it comes to language management, Alina admits that she would not mind if Mats started learning English in the future, since she can already see his interest in other
languages, especially in watching various videos on YouTube in different languages. Alina is also the only participant who admitted that the COVID-19 pandemic had brought some positive experiences to their family:
(Q: What do you attribute these improvements to?) Pandemic. Because we. We've been working from home for two years now, and he spends a lot more time with us, in a quiet environment where he feels safe. And where everything is familiar. It's just easier. It's just easier to learn. There's less stress.

In the case of Mats' family, we can see how the family where one parent is a native speaker of the majority language receives less contradictory advice and is generally supported by all the practitioners. Alina preferred not to disclose their family's yearly income, but it can be concluded from the information about their family that they belong to the middle class by Swedish standards. As a result, the family does not experience any overt or covert barriers in getting access to autism-related resources for their son.

### 5.2.4 Marina and Nikita

Marina, her husband Petr, and their three children immigrated to Spain two years ago. All of them were raised monolingually and learned foreign languages at school. They are both pediatricians, but Marina does not have a work permit yet and is staying at home. Thus, they both can be characterized as a so-called "brain-drain" transnational family. While at this moment they occupy the lower-middle-class social ladder in Spain, they will likely experience upward social mobility as soon as Petr finishes his medical residency and Marina has an opportunity to resume her career as well. Until then, the family is experiencing declassing - "loss of economic power and prestige and status which previously marked one's class position" (Block, 2017, p.140). Their family's experience in such a declassing was also happening at the start of the pandemic. Marina admits that "the main load concerning everything" rests on her shoulders because her husband works a lot and is the main breadwinner. She is incredibly open about the hardships of their immigration amid of the pandemic:

It's just very difficult with everything. Emotionally it's very hard. Because we have no friends here. We have practically no... Very few, yeah. A few times a year we meet somebody. Here. And we're in it, you know? In our own family, in our own juice, and there are complications. Difficulties regarding the middle child. Yeah, the difficulties concerning how the boys interact with each other. That's very... It's devastating. Now we've got Covid. Also, kind of... I feel like, you know, I'm in such a terrible mood afterwards. I'm in a really bad mood. It's just this kind of... Just apathy. I don't have the energy to go on with them all.

Their autistic son Nikita is 13 years old and was officially diagnosed at ten. Marina believes that even though they have noticed that he "was different from birth", Nikita's diagnosis was delayed due to practitioners' misconceptions about autism. She also admits that her oldest son's illness has affected the whole family and shifted their attention from Nikita. Marina thinks that they missed many early signs of Nikita's autistic behavior during his brother's fight with cancer. She also believes that because of Nikita's
friendliness and openness to other people, the specialists mistook his behavior for other conditions like "global speech delay".
Nikita attends a mainstream school in Spain but struggles with languages. He requires additional support and tutoring in language learning. Because he failed five subjects last school year, Marina and his school are currently looking into a possibility to transfer him to a special school for autistic children. Marina admits that such a possibility initially scared her and sent her into denial based on her perceptions and societal stigmatization of the special education system in Russia.

According to Marina, the situation is significantly complicated by the language policies in the region they currently live. Thus, Nikita is exposed to two main dialects of Spanish through society and schooling: Castilian and Valencian. Some subjects in his school are in Castilian, while most are in Valencian. The family has decided to speak Russian only at home, but Marina also believes it is important to focus on Spanish since they plan to stay in Spain. However, she is overwhelmed by learning two varieties at the same time and admits that it causes a lot of confusion. To improve Nikita's situation with both varieties, Marina spends most of her time tutoring him with school homework and making sure he memorizes new words. At the same time, they are maintaining Russian as a home language. However, she hopes that Nikita's life will be easier if they remove Russian reading and writing from this equation. Despite these language management strategies, she admits feeling uncertain about their decisions:

And most importantly, you know, I don't know what to do with him. How to help him. I really
want to help him. Because, you know, there are successes. There are successes, and it works.
But how to do it all. Speed it up? It is not clear. I don't know.
This uncertainty is amplified by advice received from teachers, who recommend speaking Spanish at home. Despite these recommendations, Marina decided to stick with their original plan to use Russian at home. She admits that relocating and adjusting to a new country, culture, and language is "complicated enough"; she wishes she "could do more in Russian" with her children and regrets not spending more time learning English with Nikita before their move to Spain. Marina believes that the financial barrier is the key obstacle to improving Nikita's language skills.

In her interview, Marina also brought up many stories of her son's diagnosis recognition. She mentioned how she was ridiculed by her relatives and specialists in Russia when she had started suspecting that Nikita was "very interesting". It took them five years to receive an unofficial diagnosis in Russia. It is clear that if it was not for Marina's persistence, Nikita might have been left undiagnosed and without the proper additional support he receives. It is of no surprise that as a medical practitioner herself, Marina is extremely critical of the issues involving autism recognition:
(Q: Why do you think it took so long to receive a diagnosis?) Incompetence of specialists.
Absolutely. Incompetence.
In comparison, Marina holds a positive view about autism recognition in Spain since they were able to receive an official diagnosis for the first time, and this process was very fast.

However, she admits that redistribution in Spain is also far from perfect. Even though her son attends many extracurricular activities, she believes that "there's not a lot of activities relative to Moscow". Thus, despite a complicated financial situation, the family invested in hiring a Spanish tutor for Nikita. However, Marina also shares some concerns about language management and autism:

> It's so different for everyone. Some people really don't need any tutors. It's going smoothly for neurotypical kids. With such difficult children - I understand that you definitely need teachers. Definitely. And that it has to be natives? That it has to be Spaniards. I'm not so sure about that right now, either. Because some things have to be explained in Russian by the teacher. You know, the grammar, right? Oh, it's very difficult. It's very difficult. I do not know, as in some kind of, I am still in a state of confusion, I do not understand.

Marina attributes a lot of confusion and uncertainties about language management and practices to the fact that they had no experience with bilingualism before their relocation to Spain. Marina believes that Nikita's major difficulties in language learning are caused by autism, not by bilingualism, even though she admits that "it's hard with languages". She is also uncertain about her son's future career prospects, but admits that it will be easier for him in Spain as it "won't be the end of the world" if he does not finish high school in comparison to Russia:

Because for me, I understand that, like. You don't have to be a person with a college degree. Somebody will be without a college degree ((laughter)). Yeah. There will be people like that. Maybe it's more likely that (name) will be without higher education.

While she casually jokes about it, it is also clear that the fear for Nikita's future is mostly centered around the possibility of downward class mobility due to the challenges from autism.

### 5.2.5 Nina and Ilya

Ilya is an autistic 7-year-old boy from Israel. His parents immigrated to Israel long before he was born, and both have adult neurotypical children from previous marriages. Both Nina and her husband grew up in Russia in monolingual families. Their family uses Russian as a home language and uses Hebrew with their non-Russian-speaking guests. Nina also adds that "Russian is for families, for studying online". Interestingly, Nina's adult children from her previous marriage speak Hebrew only, and Ilya is very critical of it - "stupid, why don't they learn Russian?". Nina points out, that Ilya was surrounded by different languages from birth and could see them use and learn languages other than Russian. She also points out that Ilya communicates with their guests in Hebrew - "he intervenes in the language of the speaker". Nina provides a detailed explanation of language practices and ideologies used in their family in one paragraph during our interview:

It's kind of perfectly fine for us to speak the language we want to speak. If we are present near a person who will not understand us in Russian, I will naturally switch to Hebrew. In order not to offend this person, so that he understands. Because people often get the feeling that - what I
don't understand - I'm afraid of it. Not everyone is like me. I'm not afraid because what I don't understand, I'll ask back. But mostly my husband and I talk to him, I address him in Russian. Because we really want Russian to be his main language. Because it's a very rich language. Hebrew is an easy math, he learned it quickly. So, there is no problem.

Ilya's parents believe that bilingualism is important and invest a lot of time and resources into Ilya's language learning online classes and tutoring. Ilya's language development is above age-appropriate, and overall, he requires no additional support in language learning. Nina believes that his social skills are the area that requires the most attention and support. Apart from ASD, Ilya was also diagnosed with ADHD and ODD. Nina believes that it is a big "assortment" of diagnoses and admits that "this assortment is growing", implying that Ilya might encounter more difficulties and receive additional diagnoses as he grows older. Nina was told by a specialist that Ilya "has a development of a 14 or a 15 -year-old" in the Russian language, so overall, she is satisfied with his language development. She believes that Ilya's problems with communication are linked only to his autism and difficulties in following social cues and having little interest in communication with his peers - "he doesn't even have a question in his head that it's indecent to ask some things". Nina also admits that Ilya swears a lot, although the family has a very relaxed attitude towards it - "we're not afraid, swearing is also part of the language".

Ilya attends a special class for children with ADHD with Hebrew as the school's official language. Nina believes that Ilya's Hebrew has improved a lot; she admits that it was "very bad" for the first two years of his kindergarten. In kindergarten, he was also constantly exposed to English through his private assistant, and Nina encouraged the assistant to speak English to Ilya. Nina also hired an additional tutor in Russian during this time; she's been actively collecting video recordings to monitor Ilya's progress and posted them on Facebook for other parents to see. Nina pays a lot of attention to the grammaticality of Ilya's language skills and points out that, because of this early intense intervention "the child has improved a lot both in Russian and with the pronunciation" and his "sentence construction is more correct" now. Although Hebrew is the official language of schooling, Nina admits that two teachers in Ilya's class can speak Russian to him "when he's having a hard time".

In addition to Russian and Hebrew, Ilya is learning English and Mandarin. He is also busy with many extracurricular activities like capoeira, and programming. There is, however, a clear distribution of responsibility between the parents when it comes to extracurricular activities: Nina is responsible for languages, and her husband for STEM activities and sports. In general, Nina is very positive about both recognition and redistribution for autistic people in Israel, even though a lot of additional educational support is received through parents' financial means, both locally and internationally.

Overall, it is clear that the family shares extremely positive beliefs about additional language learning and bilingualism:

I think it (bilingualism) develops neural connections. I believe it helps a person in the future. I
think it makes for a fuller personality. And it works for me. It suits my family. So, we do it.

This link between bilingualism and "neural connections" is mentioned by Nina several times during our interview; it seems that Nina believes in neuroplasticity and openly advocates for early intensive intervention. As a result of such a position, Nina starts looking for professional help as soon as they encounter any difficulties, especially with language learning:
> (Q: You answered that you have decided to raise your son in two main languages. Are there any difficulties in such an upbringing?) When there are difficulties, we solve them with the help of professionals. That is, we take lessons. We learn it ourselves, and we teach it with the help of professionals. That is, when we had help at school with Hebrew, then we also had help with Russian in online lessons.

Nina and her husband gave the biggest priority to spoken language and had not used alternative communication. They sought advice from many different specialists both in Israel and in Russia "because there was a long period of silence". Like many other participants, they have received many conflicting pieces of advice including those not favoring bilingualism. Nina approached all the advice she disagreed with from the position of a person who knows what is best for her son:
(Q: You answered that most professionals had advised you to raise your child in two languages?) Let's just say - I ticked the box. I basically didn't ask anyone, anyone for advice. With the doctor, who is French-speaking. Who has barely learned Hebrew, he told me that I should only speak Hebrew. I told him, "Parlez vous français, au revoir, doctor, bye bye". I don't quarrel with anyone. I listen to the advice, I digest it. But I do what I think is right. I mean, the doctor can, the doctor said so. We only saw the doctor to tick the box on the form because we had to. In order to get to a specialist. The specialist - neurologist didn't care at all. Put your hands out, put your feet out. No tremors? It's okay. Get out of here. (laughing) So that's it. There's a lot of people that go through our lives, go through, and go through. Am I going to listen to everyone's advice?

When it comes to their family's plans about languages, Nina admits that a lot of their plans were affected by the pandemic since they had to pause traveling and were forced to spend most of their time at home. As a result, she is more reluctant to develop any future plans. However, she admits that during "the family meeting" they decided that Ilya will start learning Mandarin "because more people speak it, and it might help you in programming".

### 5.2.6 Sofia and Robert

Robert lives in Sweden together with his parents and a neurotypical older sister. Sofia comes from Estonia but is a Russian heritage speaker. She also speaks Estonian, English, Swedish, Spanish, and Italian. Her husband Pablo is from Peru and is a Spanish native speaker. He also speaks Swedish and English. Pablo and Sofia communicate in Spanish with each other. Sofia admits that it "was natural for me to speak to my children in the same language that my mother spoke to me as a child". As a result, Sofia and her husband use OPOL with their children. They also use Swedish when they have guests who do not
speak Russian or Spanish. Sofia has an undergraduate degree in linguistics and is treated by her family members as an "expert" in language learning and language policy-making; not surprisingly, she is responsible for the majority of the family's language decisions. The pandemic has tremendously affected the family's dynamics with grandparents as all their contacts have switched to online only. Prior to that, the family used to visit the children's grandparents in both Estonia and Peru.
Robert is nine years old and was diagnosed with ASD when he was four. His parents started noticing his "difficulties" after comparing his speech milestones to his sister's at the same age. He has a speech delay in every language he speaks, using Russian with his mother, and Spanish with his father. While trying to improve his spoken language skills, Sofia has noticed that Robert started recognizing letters and learning the Russian alphabet from YouTube videos. She has been using reading and writing as alternative communication and a scaffolding tool for the spoken language with Robert ever since. Sofia tells me that after Robert had started writing - "he started speaking much more clearly". However, she admits that Robert "still talks like a little kid" and finds it difficult to "speak coherently" and "construct sentences intelligently".

Sofia has created many family language activities to improve Robert's language development: she photographs him while doing various activities and later shows this photo to Robert for him to describe. Sofia also keeps a journal where they write short stories about their activities together; after some time, they read these stories together aloud. Sofia believes that Robert understands everything, but "it's hard for him to express himself in a way that others can understand"; she links these difficulties to autism, and the double empathy problem in particular:

Perhaps because it is difficult for autistic people to imagine themselves in other people's shoes. And what he says is understandable to him, right? But to an outsider, it's just a flow of words. And so we try to show him how to do it. To form sentences, and how to speak coherently, so that others can understand him. And that's the way we're working with him now.

Since Robert is minimally speaking, Sofia pinpoints the area of their concerns about Robert's language development:

Because his problem is precisely with connected speech. When you can explain in short phrases and show, then he explains perfectly. The difficulty arises when he needs, for example, some abstract phenomena, feelings for example.

Robert requires significant additional support at school; he attends a special school for autistic students and autistic students with Intellectual disabilities. The school uses Swedish and alternative communication based on Swedish. The school personnel is aware that the family uses Russian and Spanish and has never discouraged them from doing it. Sofia believes that both she and her husband play an equal role in making decisions about their children's languages. They also use OPOL when reading books to Robert. Sofia only reads books in Russian - Pablo, in Spanish. Sofia believes that everyone in her son's school recognizes his bilingualism, attributing this fact to living in a neighborhood where
"no one's surprised by bilinguals anymore". While Sofia is very open in her support of bilingualism, she is hesitant to give it any definitions and explains:

> But language, you could say it's more like a tree. That is, there is a trunk, branches. The big branches break up into smaller branches, so it's a whole complex of different, different skills: speaking, reading, writing, and vocabulary in the very different areas. From all sorts of different areas. And sometimes it's even hard to tell which tree is higher. For example, a tree, one tree might be tall but thin, and another might be thick and branchy. And the third may have a thin trunk, but many, many different branches. And which of these trees is bigger? It's like that with languages. Maybe he, the child may know something. Something, for example, something he might know in Swedish, something he learned in school. But at the same time. In some other situation, it may outweigh the vocabulary in another language. So, it's very difficult to compare like that.

Without realizing it, Sofia explains the notion of linguistic repertoire by providing this beautiful tree metaphor. She later adds that she does not see any disadvantages in bilingualism but admits that adhering to bilingual practices might take more time "reading in different languages takes more time than reading in one language". At the end of the interview, Sofia links her son's bilingualism to the notion of language capital and suggests that it will not be beneficial to decrease it:

Let's say, giving up a language. Which one? (sarcastically) Swedish maybe? He doesn't speak it much anyway. But everything, all languages help him. What he cannot say in one, he may be able to say. What he can't explain to me, for example. Maybe he can explain to dad in Spanish, and vice versa. That's his language capital.

Sofia is overall satisfied with the amount of recognition and autism-related support they receive in Sweden. She believes that the school is aware of their family's bilingualism and does not object their family's language policies. She admits that bilingualism is not Robert's school responsibility, and concludes that it is foremost their family's priority, thus the school is responsible only for Swedish language management. She does admit that intermarried families like theirs often face a choice in Sweden - whose native language to keep as the so-called "mother tongue" subject at school. So far, Sofia was responsible for this decision with her older child and chose Spanish as a mother tongue for her daughter. She believes that since she works as a mother tongue teacher herself, she could be responsible for teaching Russian at home to her children. She concludes that homeschooling in Russian will give her children more than one hour per week of a mother tongue subject at school.

Sofia becomes less optimistic when I ask her about her son's future perspectives and admits that "it's hard to know what the future holds" and they will make decisions based on Robert's progress.

### 5.2.7 Konstantin and Mark

Mark is a 10 -year-old autistic boy with an intellectual mental disorder and learning disabilities. He is non-speaking and requires a great amount of assistance in his daily life
and academic learning. His parents, Konstantin and Nadya, are both from Russia and are currently studying in Sweden. They both represent the "brain drain" transnational immigration and are not sure if they are going to stay in Sweden after graduation. Mark's parents were both raised monolingually, but they also spent about two to three years living abroad with their parents and were exposed to bilingual environments.

Mark has an older neurotypical sibling. The family uses only Russian at home; however, Mark is exposed to both English and Swedish through TV, apps, books, and his sibling. Interestingly, Konstantin admits that initially they tried to use English only at home to speed up language acquisition for their older child. Since both he and his wife were proponents of immersion programs for language learning, they thought it would be the best option for their children. However, they had to switch to the ML@H model after noticing that both their children were not comfortable with using English at home. The switch to the ML@H was also recommended to Konstantin by Mark's teachers and their family therapist. Konstantin admits that they have noticed changes in their children immediately after this switch:

> When we did that, the nervousness in both children, it decreased exponentially. Literally within a week, their psychological state leveled off, and the nervousness went down. After that, the rule is that at home we speak in... Russian.

The family uses low-tech aided AAC for communication. Mark can communicate with picture cards on the word level - "if he is thirsty, he gives a card with a picture of a glass with liquid on it "; he has not learned how to build phrases or sentences with cards yet. The family has also started introducing high-tech AAC as a communication tool outside the home. Konstantin explains that they have started using alternative communication with Mark because they "didn't manage to trigger his speech", and he attributed this "failure" to their own efforts and Mark's development:

> Maybe the prerequisites were there. But either the time was missed, or he really doesn't have that potential to. Well, to vocalize, to speak like a normal person. And it took us a very long time to find a means of communication that we could understand. What he wants, what we want from him.

Mark's grandparents do not communicate with him, so he is mostly exposed to Russian through his home and his personal assistant (Avlösarservice) who also uses both Russian and Swedish. Mark communicates with a small "road set" of pictures with his personal assistant. Konstantin believes that Mark has a large conceptual vocabulary and can tell different languages apart. According to Konstantin, the latter can be especially seen from Mark's communication with his personal assistant:

And even when she (personal assistant) talks to him, he has one way of showing his body language when she talks to him in Russian or when she says something to him in Swedish. He perceives it differently, you can see it in his eyes, in the way his head moves, for example, in the corridor. So, it's some, well, in his case it's nonverbal things.

Despite having ML@H as their FLP, Marks consumes a lot of digital content in English and Swedish. Konstantin is also surprised that Mark prefers when his mother reads him
books in Swedish. As a result, he is no longer sure what language is Mark's dominant. Before the start of our interview, Konstantin even joked that Mark is an "equally silent bilingual", presumably characterizing his son as a balanced bilingual in Russian and Swedish.

Mark attends a special school for autistic students with Intellectual Disability. The school is in Swedish and uses both unaided and aided low- and high-tech AAC, and signs based on the Swedish sign language. According to Konstantin, the teachers speak to Mark in Swedish only, using the signs in Swedish simultaneously. While both the family and the school have tried introducing key word signs to Mark, he understands but does not use them, preferring the visual modality as his main method of communication.
Both parents have reclassed from the lower-middle class in Russia to being international students in Sweden. While financially they are still lower-middle class, both parents anticipate experiencing upward social mobility once they graduate. They have access to professional long-distance support: Mark's mother is consulting several specialists from Russia. Konstantin admits that the majority of controversial advice about bilingualism and advice favoring monolingualism were received in Russia. He elaborates about the reasons for differences in bilingualism recognition in Russia and Sweden: because "Russia is de facto monolingual", Russian specialists "pressure the child to learn one language" so that the child "is not confused" by additional languages. In contrast, Konstantin believes that they have not received many recommendations for bilingualism in Sweden because Swedish society "implies that it is bilingual in many ways".

Konstantin's views about bilingualism are quite casual since he believes that "the whole world is heading towards the direction that the world will speak two languages anyway". However, as they are not linked to the possibilities of upward social mobility or enriching one's language capital, bilingualism is "not an important goal or feature" for him because "you cannot make money with languages in today's world":

I don't see any pluses or minuses in multilingualism. It's like the weather. It just happens in life. And there's nothing you can do about it. You either adapt or change the conditions of your existence.

Overall, the couple is not satisfied with the redistribution of resources in healthcare and additional support with speech therapy, occupational therapy, etc., but they are satisfied with the redistribution in educational settings, praising their son's school and education practitioners for a lot of progress in Mark's overall development. Konstantin believes that Sweden "has a great potential to help such people" but does not use it to its full capacity and employs "not motivated" practitioners with "extremely weak training" to work with autistic children. Like many interviewed parents, Konstantin mentioned that the redistribution issues they encounter are "not about languages" - "the situation lies on the general plane of assistance and training specialists in this area".

While critiquing redistribution in Sweden, Konstantin highlights the high levels of recognition when it comes to Swedish society's attitudes towards autistic people. Later during the interview, he admitted that the family decided to relocate from Russia to another country primarily because of Mark's diagnosis and the stigma around it in Russia.

He painfully admits that the redistribution in Russia is good only during the child's early childhood, and after that the problems with recognition and redistribution become more prominent and intertwined. He mentioned that some measures are being done to change the stigma around adult autistic people in Russia. However, his later comment about autism in Russia is full of abyssal thinking:

> Such people have only two kinds, two futures. The first is to be, frankly, trapped within four walls while the parents with whom the child resides are going to work, working. Or it's an institution where they are held, as it were, in a closed type of institution. That is, where they have no opportunity for free movement and free schedule.

When it comes to future plans, Konstantin separates them into two categories. The first one has to deal with their experience as a transnational family and prospects of upward mobility. Since Konstantin believes that their family has "no one else to rely on", he admits that their future depends on the availability of work and the ability "to develop the child further". The second category has to deal with concrete perspectives for Mark's future employability; Konstantin's answers about it are full of abyssal thinking linked to the possibility of their return to Russia:

> If everything succeeds, we'd like... Probably for (name) to finish school. At least in Sweden. And get. If possible, some kind of working specialty, so he could support himself later on. And live independently, away from us. And if that fails, then we will most likely change the country to one where the attitude is... To people with his condition is friendly. If somehow we fail completely everywhere, we can always go back to Russia. There will also be, on the one hand, good help there, but only until he reaches the age of 18 . After that, the situation will dramatically collapse.

Overall, Konstantin's interview has many intersections between bilingualism, autism, and social class. He clearly puts them into one constellation of challenges that affect their family's FLP. There are many similarities between his interview and Marina's - both parents belong to "brain drain" transnational families and do not hesitate to mention their immigration-related stress as one of the variables affecting their family lives.

### 5.2.8 Vera and Artem

Artem is a 9-year-old autistic boy living in Lebanon with his parents and a neurotypical older sibling. Artem's mother, Vera is from Ukraine. She is a Russian native speaker and also speaks to various degrees of proficiency Ukrainian, Arabic, French, and English. Her husband is Lebanese and is bilingual in Arabic and French. He also speaks English. Thus, both parents were raised bilingually and were exposed to bilingualism through their schooling. The parents use translanguaging in communication with each other but use OPOL with their children: Vera speaks Russian to her kids, while their father uses a Lebanese dialect of Arabic. Interestingly, Artem chose French, his main language of schooling, as his dominant language and has the highest proficiency in it in comparison to Russian or Arabic. He communicates with his brother in both Russian and French. In contrast, his brother uses OPOL with his parents. Vera admits that they decided to use

OPOL with Artem since it worked well with their older child, who differentiated both Russian and Arabic from the beginning - "Russian is like mama", "Arabic is like papa". Vera feels a very strong connection to her first language and believes that "it would be a crime for me to take away Russian". While she is happy that her son is developing his spoken language skills through French, she feels that it is strange, as "usually the mother's language is chosen". Such regret is typical for "minority mothers" in intermarried families when the "invisible work" in maintaining their minority language does not lead to successful acquisition of the mother's native language (Doyle, 2013).

Vera tells me that Artem's diagnosis was delayed, and he was initially diagnosed with ADHD because the specialists believed that "there are a lot of languages in the family". Despite the late diagnosis, Vera admits that they "don't have big issues" with Artem since he communicates with her "through his phone" after he learned how to read and write.

Artem attends a private school for children with special needs. He understands all the languages used at home and outside the home but prefers using French. Vera believes that it is better to gradually introduce him to reading and writing in Arabic and Russian since Artem requires some additional support in learning and developing his language skills. Vera characterizes Artem's current language development by pointing out that Artem is not fluent in any language. Like many interviewed parents, she does not link it to bilingualism and exposure to additional languages at school but to his autism:

> I mean, he can't directly explain something there. That kind of thing. I mean, he can explain it to me. He's afraid to say it to a stranger. That's, it's not even languages, it's that he's autistic.

Since Artem has situational mutism, the school also actively uses gestures in communication with him. However, according to Vera, as his language skills are constantly progressing, Artem has been relying less frequently on gestures.

The family received much negative advice from professionals at the beginning of Artem's diagnosis, with some specialists advising Vera to stop using Russian. The parents decided to stop seeing these specialists and found new ones who were supportive of their family's bilingualism. While Vera believes that there is no harm in bilingualism, she is also afraid that Artem "will mix languages" and decided to wait with teaching him how to write in Russian until French "is settled in his head" and he masters Latin and Arabic scripts. Overall, Vera believes that they will be focusing on learning French as Artem's dominant language, but she does not plan to subtract any other language used in their family. She also admits that "removing" a language from their family's repertoire as initially advised by practitioners, could make their lives easier and it will make the progress much faster, but she decided to keep all their family languages:

[^5]Vera admits that Artem's spoken language skills are good enough for the family members to fully understand him but admits that "with other people it will be more difficult". Vera and her husband had positive attitudes towards bilingualism from the beginning - both were exposed to it since childhood and saw many examples of successful bilinguals within the Russian-speaking immigrant community in Lebanon. Vera is an active member of this community and admits that witnessing other people's language practices has guided her language management strategies with her children.

While the family belongs to the lower-middle class and neither of the parents has a university degree, Vera and her husband invest a lot of resources into their children's education. Thus, Artem's private school is also paid for from the parents' pockets; Vera admits that public schools in Lebanon do not meet their standards for high-quality education, and as a result, she feels like they had no other option than to send Artem to an expensive private school. Vera also points out experiencing the same issues with healthcare - the family has to pay to see private practitioners who meet their requirements. Dissatisfied with the redistribution, Vera believes that without sufficient income to support their autistic son, they would not have received enough support from the government. While praising the societal recognition of autistic people, Vera also mentions the double standards she has experienced as a minority mother when looking for professional views about raising Artem bilingually. She confronted the specialist who was advising her husband to "remove Russian" by pointing out that the Armenian diaspora in Lebanon has even more languages and the specialist does not advise her Armenian patients to "remove" one language. What frustrated Vera the most in that situation was that the specialist tried to convince her husband to abandon Russian without consulting Vera herself. She mentions encountering similar double standards several times and points out the ridiculousness of such recommendations given that the majority of Lebanese people are fluent speakers of at least two or three languages:

So naturally, when I'm told by specialists to remove the language (Russian) - I look at them and say, "Do you tell the same thing to the Lebanese people, right?" I mean. And just. And just like that. Why else. Why else say that.

Like many interviewed parents, Vera concludes that Artem's issues with language development are not linked to bilingualism but to autism - "because he's autistic it's hard for him to communicate".

## 6. Discussion

This study aimed to investigate the language policies and practices of transnational families with bilingual autistic children and to see to what extent the existing FLP frameworks can be used to describe these families' lived experiences. First, I wanted to
look into the reported family language repertoires, practices, and beliefs in these families. I also wanted to investigate how the presence of additional diagnoses, speech development, and other factors affect the parents' decisions about bilingualism. To answer these questions, I used a combination of data obtained from the parental questionnaire and follow-up semi-structured parental interviews. In addition, the qualitative data from the interviews was used to examine what other broader ideologies and discourses of bilingualism and autism were present in the parental accounts. The main theoretical question I wanted to answer was if the existing FLP models can cover all the dimensions of these families' lived experiences.

### 6.1 What family language practices, ideologies and management strategies are reported in questionnaires and interviews by transnational families of bilingual autistic children?

### 6.1.1 Language practices

The results of the study indicate that the most popular FLP model at home was a monolingual one - ML@H, followed by MLU, MajL@H, and OPOL - as the least "favorite". The latter is especially interesting since OPOL is the most studied and published about model in FLP research. OPOL was predominantly chosen by families where one of the parent's first languages was a majority one. Among my participants, Maj@H was predominantly used in English-speaking countries or families with English as their main work language. Not surprisingly, ML@H was the most popular model in families where both parents share the same first language and none of them is a native speaker of the majority language. These families were also the ones to often receive professional recommendations to favor the majority language. While the data from the questionnaire suggests that families of non-speaking autistic children received more advice favoring the majority language, the data from the interviews paints a more complicated picture. Judging from the interviews, the majority of such recommendations were linked to whether at least one of the parents was perceived as a racialized bilingual by those practitioners. However, while some of my data contained experiences of racialization, the sample does not provide sufficient grounding to explore race or ethnicity in relation to my research questions in depth. As a result, this analysis will focus on social class as one of the major components of autistic people's and their family members' complex and nuanced identities.

It is interesting to note that out of 40 autistic children, only one can be characterized as having monolingual only exposure (at least so far). Is then monolingualism even possible within the lived experiences of transnational families? It seems that it is only achievable when the child is too small to attend kindergarten or school, the family lives in a predominantly monolingual country (e.g., Poland or the USA), and/or when the parents deliberately gatekeep their child's access to any digital content, or strictly monitor what languages are chosen by the child. Overall, most parents admitted that their autistic children watch digital content in "all languages", leading some parents to the conclusion that their children do not care about languages at all. However, the same parents often
noticed that their children switch to the languages of interlocutors. In these accounts, parents also believed that their children differentiate between languages. I think, the double standards in these interpretations by parents often came from the fact that in the former example they regarded languages as named entities, while in the latter - as their child's whole language repertoire. While it is important to shift from the monoglossic view of named languages to the heteroglossic model of language repertoires, parents used the notion of named languages when arriving to many assumptions and conclusions.

In contrast to screen time, the children's reading language often matched the minority language or the dominant language of their mothers. It is clear that the choice of reading and watching digital content was often linked to the agency of minimally speaking and non-speaking children - these were the rare occasions when the children were the driving forces in language choices and practices.

Unfortunately, less agency was being granted to non-speaking and minimally speaking children when it came to alternative communication. While most parents who used alternative communication did so in at least two languages, kindergartens and schools were favoring monolingualism, using the majority language only. Overall, parents preferred using simple family gestures and low-tech AAC like visual schedules and images with text like PECS with their children. However, many parents abandoned alternative communication as soon as their children started using words or learned how to write.

The preference for spoken language as the most desired interventional outcome and favored modality was clear from the parental discourse about alternative communication. Thus, among the parents who considered using high-tech AAC or were already using it, the majority admitted that this decision was made because they "failed" to develop speech. The narratives involving AAC were often linked to the abyssal thinking, where parents played a role of an ableist listening subject, perceiving alternative communication as inferior to speech. Moreover, speech or lack of it was often the primary reason many parents noticed that "something is wrong" and started looking for an official diagnosis and help.

Parental discourses were also often focused on the language practices and management of schooling. This was especially relevant to parents since their children spent most of their workdays at school. The results suggest that most of the schooling is still monolingual, and most of the advice to give up minority language was given by educational practitioners in native English schools. Interestingly, educational practitioners were less favorable towards bilingualism in comparison to healthcare practitioners.

### 6.1.2 Language ideologies

The data from both the questionnaire and the interviews suggests that parents of autistic children from transnational families were overall supportive of their children's bilingualism, with the majority choosing to raise their children bilingually. In families with both autistic and non-autistic children, bilingualism was more important for non-
autistic children, and bilingualism was ranked more important for non-autistic children when their autistic sibling is non-speaking. The results also show that the majority of children had bilingual exposure at home, even though many participants were using monolingual FLPs like ML@H and MajL@H.

Parents who had been exposed to bilingualism in childhood themselves had even more positive views about bilingualism. Most parents were opponents of subtractive bilingualism and believed that it is hard to "remove" one language. However, thy also admitted that subtractive bilingualism would be an easier way out and save them a lot of time and effort in raising their autistic children. Overall, parents who are not native majority language speakers did not demonstrate any concerns that their autistic children will "lose" competency in their minority language after exposure to the majority language. Quite the contrary, several participants mentioned that learning additional languages "develops the brain" and "builds neural connections". In contrast, parents who used OPOL showed signs of worrying that their autistic children are not becoming balanced bilinguals as they initially hoped. For example, both Mats and Robert's mothers were concerned about their slow progress in learning Swedish (the majority language). However, it is important to highlight once again that they did not see it as a result of bilingual upbringing, connecting these difficulties to autism and their issues with speech development in general.

Despite positive views about bilingualism, some interviewed parents believed in a certain hierarchy within their autistic child's language repertoire. For example, several participants mentioned waiting until the most important language "settles in" before studying the new one or introducing writing and/or reading in the minority language. Positive views about bilingualism, however, were often voiced alongside beliefs that native input is better for autistic children - the parent who is not a native speaker of the majority language was usually discouraged from using it with their children; this belief often correlated with the chosen FLP model.

Unlike participants in previous studies, the majority of interviewed parents admitted the ridiculousness of restricting the child's access to other languages. Since there were no statistical differences in many pairs of statements about the importance of bilingualism for autistic and non-autistic children, we could be witnessing a potential change in parental attitudes towards bilingualism, at least within transnational families. However, these beliefs about bilingualism were less optimistic among parents of non-speaking autistic children. While they did not perceive bilingualism to be an obstacle and believed that their child would struggle as much if they had been raised monolingually, they also did not associate any particular advantages with it. Instead, they matter of factly saw it as another variable they need to consider when seeking additional support.

Most parents also highlighted the importance of English as a majority language in many countries of residence and due to career paths chosen by the parents themselves. Indeed, it was the most often mentioned home language among the participants. This is interesting, considering that only nine children from the questionnaire live in Englishspeaking countries.

### 6.1.3 Language management

The top three most popular language management strategies were linked to the language of schooling and language choices for screen time. These included sending the autistic child to a school with the majority language as the language of schooling and giving the child access to digital and analog content in several languages. Most of the interviewed parents admitted the importance of digital content for both language development and learning in general. The amount of exposure to digital content and communication has increased even further during the pandemic.

Another important finding was that parents had no problems with understanding their children's requests and communication, they were more worried that the outside world does not understand them. All interviewed parents agreed that their autistic children adjust their language to the language of interlocutors. As a result, most of the language management strategies were aimed at the facilitation of spoken language skills and pronunciation in particular. Such a focus on good pronunciation was especially evident in families where children's language development is not significantly delayed. It is possible to hypothesize that such a focus on pronunciation and speech therapy as a preferred remedy shows how parents can sometimes play a role of the ableist listening subject. However, it is also likely that parents acted in an attempt to minimize "othering" of their children by broader ableist listening subject - the society in general.

Consistent with the literature, the results of this study suggest that mothers played the most important part in maintaining minority language and logistics for communication with distant family members. Several participants also mentioned that they, as mothers, do most of the work when it comes to finding support, visiting specialists, and dealing with most aspects of autism redistribution. Additionally, all single parents in this study were mothers. However, many interviewed participants also highlighted that they try to make all the important decisions together with their spouses. Interestingly, fathers were usually responsible for stereotypically male activities such as extracurricular sports and STEM activities, while mothers were responsible for managing activities and strategies that could be combined under an umbrella term of "humanities". However, these observations need to be interpreted with caution, as the majority of the interviewed parents are of Eastern European origin, thus, they could be sharing similar cultural backgrounds and gender stereotypes.
While in the following section I will argue that autism plays one of the most important roles in FLP, the presence of neurotypical siblings also affected language management strategies. According to my findings, if the autistic child is a second born, parents usually based their language management strategies on their previous experiences with older children. Moreover, a lot of management strategies and early interventions were based on comparisons of autistic children with their neurotypical siblings. Comparing the age when certain milestones were reached by both autistic and neurotypical siblings usually resulted in abyssal thinking of their parents when neurotypical development was perceived as a norm, while autistic development was met with an ableist gaze. However, parents of autistic children without any siblings showed similar abyssal thinking; the comparisons were thus made not with siblings but with someone else.

Overall, parents were fully aware that there are different language policies and strategies when it comes to bilingualism. While not knowing the name of such strategies, they were able to see how they could potentially benefit or hinder from each FLP strategy. Parents were also very confident about their language management strategies and worried the most about the amount of professional support they receive for language maintenance and learning.
It could be summarized that the most popular language management strategies among parents of bilingual autistic children were similar to development strategies used by families of monolingual autistic children - increased amount of speech therapy as a remedy for speech delay, access to language tutors, and redistribution aimed at developing speech as the favorable modality.

Language management strategies in families with non-speaking autistic children, however, showed some differences. In the section that follows, I will describe all the other potential factors influencing parental decisions about bilingualism, focusing on parents of non-speaking, and minimally speaking autistic children as the main example.

### 6.2 What factors other than language(s) affect parental decisions about bilingualism?

The analysis of both the questionnaire and interviews also indicated that despite exposure to bilingual environments outside the home, the majority of autistic children are attending school in the majority language only. Majority language was also used as the only language of alternative communication in schooling, while the parents tended to use bilingual alternative communication at home. Thus, the findings suggest, that language of schooling was one of the most important factors affecting autistic children's language repertoires. This is interesting, as many parents relied on school as one of the places that provides bilingual exposure to their autistic children. While in reality, most schools provided monolingual only exposure favoring the majority language. Some parents realized this and were using ML@H FLP to counterbalance the overwhelming exposure to majority language at school.

Despite the importance of language exposure outside the home, most of the interviewed parents agreed that autism, speech development, and additional diagnoses are affecting their decisions about bilingualism. However, as could be seen from previous sections, these decisions predominantly influenced the amount of assistance in each language, as well as teaching how to write and read in minority languages. Thus, many parents built a certain hierarchy in language and development assistance for their children favoring the majority language.

Parents of non-speaking or minimally speaking autistic children were often facing more complicated choices linked to the problem of redistribution and named languages. Is there access to AAC in the family's minority language? If not, families often had to make several important decisions that inadvertently led to the promotion of the majority language. This situation was especially critical in families using high-tech AAC: the language choice usually depends on the decisions made by manufacturers of AAC
software. Here, unfortunately, the most favorable, commonly used languages for AAC devices are those of the Global North.

Among other factors that influenced parental decisions about bilingualism was undoubtfully access to redistribution. While the majority of the interviewed families live in countries with universal healthcare that in theory provide equal access to resources to everyone, the reality is more complicated. My data suggests that every family has sought or constantly seeks other opportunities to provide additional support to their autistic children. The arithmetic is straightforward - the more money the family has, the more support the child receives. Thus, families with lower SES are often left only with redistribution provided by their current country of residence. To what extent does it influence their decisions about bilingualism? While my findings cannot be extrapolated to all autistic children, it could be argued that limited access to redistribution forces parents of bilingual autistic children to focus on the majority language.

One unanticipated finding was that extended family did not play an important role in FLPs of transnational families with autistic children. The majority of interviewed parents and the questionnaire data suggest that the views of extended family members were appreciated but not considered during the final decision-making about bilingualism. However, this data must be interpreted with caution because none of my participants cohabit with extended family members, and the pandemic has significantly affected the families' transnational movements.

When it comes to professional recommendations, despite an increase in advice favoring bilingualism, especially in comparison to previous studies (e.g., Cheatham \& Lim, 2020; De Houwer, 2021; Kay-Raining Bird et al., 2012), this study confirms that the majority of parents continue to receive conflicting advice about bilingualism from practitioners. However, some parents showed that this advice is not necessarily followed and is often taken with a grain of doubt, especially by parents who position themselves as experts in both bilingualism and autism. As a result, many interviewed parents spent a lot of time on self-education and studying scientific publications about bilingualism and autism; they often concluded that not all healthcare and education providers shared the same knowledge and thus, their advice could be disregarded.

### 6.3 What broader ideologies and discourses of autism and bilingualism are present in the parental accounts?

As was mentioned in the previous section, parents of autistic children receive a lot of contradictory advice about bilingualism, despite an increase in advice mentioning bilingual advantages. I link the amount of these advice not to the number of additional diagnoses and verbality of autistic children, but the wider ideologies such as class and ethnicity. My findings suggest that racialized and marginalized bilinguals often receive advice favoring the majority language, while at the same time getting less autism recognition, redistribution of autism resources, and help.

Despite the fact that the questionnaire in this study included several questions to investigate the families' SES, the obtained data was not representative enough and could not provide deeper insights into notions of class and social status of each family. Simply judging from the questionnaire, it would be difficult to group the participants into one category. Thus, I decided to investigate the intersectionality between autism, bilingualism, and other potential ideologies in play in the interview part of this study. Even though all the interviewed families were transnational, they represented smaller clusters of class like lower-middle-class "brain drain" families, intermarried couples from different ethnical backgrounds, and families that are typically characterized as "expat" or "immigrant" based on their ethnicity rather than class (Koutonin, 2015). This finding is consistent with Block's (2017) remark that people from the abovementioned categories "embody class-inflected subjectivities in their home contexts and they do so in their new host environment" ( p .134 ), often experiencing declassing or reclassing as an unavoidable part of migration. As a result, many of the interviewed families in this study were forced into different class through migration.

While investigating SES was not the primary goal of my interviews and I avoided direct questions about potential economic and social obstacles, the participants provided a lot of information about it when replying to my questions about autism recognition and redistribution. In fact, the focus of most interviews quickly shifted from bilingualism to autism, and from autism to general issues in autism recognition and redistribution.

Most of the interviewed parents live in countries with affordable and universal healthcare where redistribution rarely occurs before recognition. As a result, it is understandable that issues surrounding both were the predominant talking points during the interviews even though the majority of questions were aimed at discovering families' language repertoires and ideologies. For example, many participants mentioned problems with receiving a diagnosis when a child is older than three years. This seemed to be a recurring pattern in many stories and is linked to the stereotypes about autistic people as unsociable savants and failure to recognize anything that does not fit this stereotype as autism. Such issues of ableist gaze are major obstacles in autism recognition.

The parental discourses involving autism recognition and redistribution were often filled with examples of abyssal thinking. When narrating their experience encountering professional advice, many professionals were painted as ableist listening and speaking subjects. Abyssal thinking was also present in several parental discourses and often intersected with their hopes for additional support and for their autistic children to become "like a normal person". The request for fair access to additional support was predominantly focused on receiving more hours of speech therapy as speech continues to be one of the main factors parents want to improve. "Normal" speech is what many parents considered to be an important aspect of being a "normal person". Thus, unfortunately, some parental descriptions of what is "normal" and what is not were clear examples of abyssal thinking that I suggest calling "ableist thinking".

Ableist thinking was constantly present in speaking about the future of language development and the potential employability of autistic children. Parents did not have high expectations and doubted that their children will receive higher education. Such
doubts are not unreasonable - my interview with Isabelle, whose son is an autistic adult, showed that access to autism-related resources and recognition is even harder to get when an autistic child matures into an adult. Parents whose autistic children have additional learning difficulties and/or intellectual disabilities sounded even more pessimistic and provided more examples of ableist thinking.

Most parents admitted that they would be satisfied if their autistic children could become blue-collar workers. For the majority of parents who hold a post-graduate degree, this was linked to the ableist thinking and fear of downward social mobility for their children. This ableist thinking is rooted in deeper issues with recognition and redistribution. Even though interviewed parents admitted that "no autistic children are the same", they tended to make generalizations based on their child's particular needs, difficulties, and successes while othering autistic people who have different needs and manifestations of their diagnosis. Even though some parents claimed to be proponents of the neurodiversity movement, their discourses still exhibited examples of othering by excluding nonspeaking and minimally speaking autistic children with intellectual disabilities.

A lot of parental concerns were also intertwined with issues related to immigration. Amongst native Russian speakers, ableist thinking was also linked to their fears of the post-Soviet correctional psychiatric system. In these examples, however, it was not the parents who used ableist thinking - they portrayed the correctional psychiatric system as a symbol of it. As a result, some of them were transferring this thinking to the educational systems of their current countries of residence and saw healthcare and education providers as ableist listening subjects.

It is easy to critique parents for low expectations when it comes to their autistic children, especially in comparison with their neurotypical children, however, it will not change the fact that it is often a result of their lived experiences within the ableist society that often limits their access to both recognition and redistribution and acts as an ableist listening and speaking subject. Functioning labels like "high functioning" and "low functioning" are the biggest part of the ableist speaking subject's lexicon: while "high functioning" autistic children are often denied redistribution, "low functioning" children's agency is often disregarded by society and/or their families. As a result, families of autistic children and autistic people often have to fight for recognition that is not solely rooted in the medical and social models of disability.

These important aspects of autistic lived experiences are simply not present within the FLP framework. Meanwhile, the interviewed parents were extremely aware of and ready to discuss all the challenges surrounding both recognition and redistribution. Thus, every interviewed parent acknowledged societal recognition of autistic children in their current countries of residence, especially in comparison with their countries of origin. However, all parents were worried about the issues with recognition and redistribution when their children will become autistic adults.

### 6.4 To what extent are current FLP models able to capture all the lived experiences of transnational families with autistic children?

The discussion from the previous sections leads us to the main issue that I see in current FLP models - its inability to incorporate lived experiences of transnational families. When autism is introduced as an additional variable to those lived experiences, it becomes even more difficult to provide appropriate descriptions using the existing FLP framework.

FLP in its most popular interpretation as a model that combines language practices, language ideologies, and language management is a functional framework for questionnaire-based studies of neurotypical populations. Indeed, using this framework for creating a questionnaire about parental language beliefs and practices reveals a lot of information, especially if the researcher includes several open-ended questions. However, data from the interviews showed that the questionnaire in this study was not sufficient to elicit all the information about the families' lived experiences. Many participants did not include important information about their language practices and management strategies in their replies or simply forgot about some. For example, many parents with Russian as their first language did not mention the fact that they were raised bilingually as children and did not consider themselves to be bilingual. Despite that fact, it is clear that their own experience of bilingualism is shaping their ideologies toward languages.

When it comes to language ideology, this part of the FLP model was the hardest one to elicit views about. While the questionnaire asked direct questions about attitudes towards bilingualism in general and in some specific areas like its relation to future employability, the interviews showed that many more angles and variables formed the parents' language ideologies as summarized in section 6.1.2.

Moving on to language practices and management, I propose changing these terms into "semiotic practices" and "semiotic management" when addressing FLP in families where spoken modality is not the only one present. This is especially the case for families with non-speaking or minimally speaking autistic children, whether bilingual or not. Semiotic practices and management are more suitable terms to describe the language repertoire of an autistic person and the management strategies of their family members; it includes both spoken, visual, and gestural modalities and can be used to describe practices associated with the use of both low- and high-tech AAC.

Thus, I believe that the current tripartite FLP framework cannot adequately describe the lived experiences of transnational families with bilingual autistic children. Unlike Spolsky (2022) who puts an unbalanced weight on the importance of family language environment and believes that it "accounts for the difficulties faced by managers at other levels" (p. 24), medical and social models of disability, as well as ableist thinking provide external influences that are too important to ignore. The notion that the family is supposed to be held responsible for "unsuccessful" language acquisition assumes that family members have all the power and resources to maintain their minority and majority languages (Bozalek, 1994), which is simply not true in the case of transnational families with bilingual autistic children. Such a position also conflicts with parents' beliefs that school and early intervention are the most important factors in their children's lives rather than their upbringing and language environment at home.

Thus, I propose a new updated critical theoretical framework to describe the lived experiences of transnational families with autistic children (see Figure 7). While the traditional FLP model only addresses the framework's central green triangle, I propose that additional spheres be added to provide more opportunities for an adequate description of the complexity of bilingual autistic children's lived experiences and language repertoires. The constellation of blue spheres represents the influence of autism, verbality, and any additional diagnoses that can be often linked to ableist thinking. The constellation of pink spheres describes all the other variables such as the child's ethnicity, gender, and class that play a role in determining access to resources and recognition. This constellation is linked to abyssal thinking as a potential form of injustice influencing racialized people's lived experiences. All these spheres can potentially contribute to the ableist injustices experienced by an autistic person and their family. The figure also incorporates the notions of recognition and redistribution that are always present and influence the FLP. Enhanced or increased recognition and redistribution are proposed remedies to these injustices.


Figure 7. Suggested model of critical FLP for transnational families with bilingual autistic children
I believe that the suggested model can be used to describe the lived experiences of families with autistic children in general. For example, the middle part that includes an updated FLP model can also be used to describe decision makings and beliefs in monolingual families that are deciding whether to introduce alternative communication. As a result, this model can be used not only by sociolinguists but also by education policymakers, educators, and speech therapists when assessing families' practices and
ideologies. It can illuminate potential obstacles in semiotic management strategies and promote other modalities than speech.

### 6.5 Limitations of the study

As I have already mentioned in the methodology section, this study has several limitations. The data from the questionnaire is not representative enough to make any generalizations about families with autistic children in general. Thus being said, I think it provides possibilities to make certain generalizations about transnational families and their lived experiences. However, data from the interviews suggest that despite being detailed, the questionnaire could not show any additional challenges and attitudes towards autism and bilingualism outside the traditional FLP model. When it comes to the questionnaire, it was impossible not to notice a high abandonment rate; some participants complained that the questionnaire was too long, thus, it would be beneficial to update the questionnaire to be shorter or include a reward for completing it.

Another limitation of this study is the SES profile of the participants. Despite trying to recruit a more socioeconomically diverse group of participants, the majority of parents in this study have a higher education degree and belong to the middle class. Although I believe that many of the participants are not perceived as belonging to the WEIRD population in their current country of residence, most of them live in WEIRD countries, are white, and are experiencing certain privileges in comparison to racialized parents.

One of the major limitations of this study was time and the pandemic. Due to both factors, I was unable to conduct my research as I initially planned it: I hoped to conduct offline interviews and take fieldnotes while visiting my participants at their homes, with family observations during lunchtime as the final step. Unfortunately, due to the time limitations and safety considerations related to the pandemic, I decided to switch to the digital interview taking. While I believe that digital format provides certain benefits that were discussed in more detail in section 4.4.2.2, adding an ethnographic study of participants' home language practices would be beneficial.
Another limitation that to some extent did not depend on me is the predominance of mothers and boys as participants for both questionnaire and interviews. While this limitation is representative of the statistics for autism in general, it would be interesting to further investigate how gender plays a certain role in both autism recognition and redistribution.

This study is solely focused on parental perspectives and therefore does not give any agency to autistic children themselves. I was not sure what demographic would be dominant in my questionnaire and was initially hoping to get more participants with nonspeaking or minimally speaking children and focus my research on them. However, many of the children of my participants could have provided interesting perspectives describing their own experiences of bilingualism. Nonetheless, it would have made this thesis too large in scope.

I plan to keep in touch with all of my participants in the hope to interview them and their autistic children when they become young adults.

### 6.6 Recommendations for future research

This study investigates reported language FLPs in transnational families with bilingual autistic children. Naturally, what parents report to be doing does not necessarily equal what they actually do in their daily lives. Just like the interviews showed that the participants forgot or did not think to mention some facts about their families, real-life observations could probably reveal some practices not mentioned during the interviews. Indeed, observing families during their daily routines like lunch or family quality time can provide a more detailed picture of a family's language practices and management strategies. There is a research gap in ethnographic studies of transnational families with autistic children, and families with non-speaking autistic children, in particular. Thus, I hope that further research will be conducted into this group of families, as well as research on autism, class, and race through an intersectional lens.

As stated in the previous section, there is a need for research on autistic perspectives in the field of FLP, especially for non-speaking autistic people who use alternative communication. Another potential angle that to my knowledge has not been investigated yet - the perspectives of bilingual neurotypical siblings in families with autistic children. Overall, there is an increasing need to study bilingualism and alternative communication, as my results suggest that some tools for AAC, especially high-tech tools, offer limited possibilities in terms of language options.

Bilingualism and AAC should also be investigated within the educational settings since this is where many autistic children spend most of their time. Both replies to the questionnaire and interviews suggest that parents had limited knowledge about language and modality practices used in their autistic children's classrooms. Most of their answers about attitudes towards bilingualism held by educational practitioners were speculative and need to be verified.

## 7. Conclusion

The present study has been one of the first attempts to question the usability of the FLP framework for families with bilingual autistic children while investigating their reported family language repertoires, practices, strategies, and beliefs. It also aimed to find out what other broader ideologies were present in the parental discourses. It has thus provided a more in-depth understanding of the impact of these ideologies on parental attitudes toward bilingualism, often mediated by professional advice. Answering these questions helped to design a new critical FLP model that could potentially provide a better description of these families' lived experiences. Thus, this thesis extends Spolsky's FLP model (2004, 2022) by adding additional areas linked to neurodiversity, autism recognition, and redistribution (Danermark \& Gellerstedt, 2004; Fraser, 1995). Given the range of assistive technologies, modalities, and associated repertoires used by nonspeaking and minimally speaking autistic children, this thesis suggests using the terms
"semiotic practices" and "semiotic management" instead of the terms more commonly used within the FLP framework "language practices" and "language management". This significant change could incorporate different modalities and modes of communication other than spoken language, allowing for more diverse populations' lived experiences to be accommodated.

The analysis of semiotic practices and semiotic management strategies shows that while the majority of families reported using a monolingual FLP at home, their actual FLP is more bilingual than they report. The results have also shown that the majority of transnational families with autistic children supported bilingualism and tried to maintain their minority language at home. The second major finding was that reported parental attitudes towards bilingualism for non-autistic and verbal autistic children were similar, however, there was a minor difference in attitudes in families with non-autistic and nonspeaking autistic children. While parents of non-speaking autistic children were generally more worried about the amount of professional advice they receive, the study has found that professional advice given to parents of non-speaking autistic children were as contradicting, as to speaking autistic children, despite a significant preference towards monolingualism by educational specialists. In contrast, healthcare specialists and nonspecialists' advice from social media, family, and friends seemed to be more favorable towards bilingualism.

There was constant conflict between the parental desire to develop a language of economic advantage and the wish to maintain the minority language to communicate with family members; the same contradictions were observed with the desire to promote spoken language over other modalities. As a result, spoken language was often considered to be the main goal and the sign of successful language acquisition, while alternative communication was often regarded as a scaffolding technique to launch spoken language. It was commonly abandoned as soon as the child started developing speech.

One of the most important findings to emerge from this study is that all the interviewed participants linked major occurring challenges with language maintenance and language learning to autism, not bilingualism. As a result, many interviews were filled with abyssal thinking regarding future potential employability of bilingual autistic children and their differences from "normal people". This study proposes to call such thinking "ableist thinking".

To address these major findings and provide a better description of autistic lived experiences, this study establishes a new theoretical framework that incorporates FLP, neurodiversity, and social justice with autism recognition and redistribution of resources. This model can be used by practitioners working with autistic children and their families and potentially improve their access to bilingual resources as well as their lived experiences.

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## Appendix A

## FLP Parental questionnaire

## Language Policies in families of bi/multilingual children with Autism Spectrum Disorder (ASD)

1. Thank you for participating in this questionnaire!

My name is Anna Metreveli, I am a MA student from Stockholm University. I want to ask you to participate in my Master's thesis project about family language policies in families with bi/multilingual children with Autism Spectrum Disorder (ASD).

If you agree to participate, this will mean that you would fill out the questionnaire about your child with ASD. The questionnaire consists of three sections and will take about $10-25$ minutes to finish. The questionnaire is completely anonymous. You can return to your previous answers at any time and change them if needed. Please fill in the questionnaire only if you are the child's primary or secondary caregiver.

You will be offered an opportunity to have an additional remote interview with me and asked to leave your e-mail address at the end of this questionnaire if you want to. Participation in this research is completely voluntary and does not offer any monetary compensation.

At any time, you can choose to no longer participate and you do not have to say why. If you no longer wish to participate before finishing the questionnaire - just stop and close the questionnaire. If you no longer wish to participate after filling out the questionnaire, you must notify the person in charge of the project (see contact details below). Withdrawal from this questionnaire will not imply any disadvantages or repercussions.

Any personal information that can be linked to you is considered personal data in accordance with the EU General Data Protection Regulation 2016/679 (GDPR). Stockholm University is the controller of this processing of personal data. According to the EU General Data Protection Regulation (GDPR) and national supplementary legislation, you have the right to withdraw your consent at any time, request access to your personal data, have your personal data rectified, erased, or restricted.

If you wish to invoke any of these rights, you should contact the researcher responsible for the project (see contact details below) or the data protection officer at Stockholm University (dso@su.se).

If you are dissatisfied with the way your personal data are processed, you have the right to file a complaint with the Swedish Authority for Privacy Protection (Integritetsskyddsmyndigheten). Information about this can be found on its website (imy.se).

The answers will be used for research purposes only and nobody else except the researcher and their supervisor(s) will have access to them. Unauthorized persons will not be able to access the data. The data will be used for the thesis and related seminars and/or conferences.

You will be able to partake of the results of the study by accessing the published thesis on Stockholm University DiVA platform on its website su.diva-portal.org. If you have any questions or concerns - please contact the researcher at anme7664@student.su.se (or annametreveli@gmail.com).

1. I give consent for my responses to this questionnaire to be used in a MA thesis research at Stockholm University. (You must select "Agree" in order to take part in the questionnaire)

Agree
Disagree

First, I am going to ask you some questions about you and your child with ASD.
Answer the questionnaire only if you are the child's primary or secondary caregiver.
2. I am the child's ...

Mother
Father
Legal Guardian
Other (please specify): $\qquad$
3. Who is another primary caregiver of your child (Caregiver 2)?

Father
Mother
N/A
Other (please specify): $\qquad$
4. What is your household's yearly income level?

0-200.000 SEK

- 200.001-300.000 SEK
- 300.001-400.000 SEK
400.001-500.000 SEK
500.001-600.000 SEK
600.001-700.000 SEK
700.001-800.000 SEK
800.001 SEK or more

Prefer not to tell
5. What is your current level of education?

No schooling completed
Some school, did not attend high school

Some high school, not completed
High school graduate, with a diploma or the equivalent
Trade-technical-vocational training-Komvux
Associate degree
Bachelor's degree or equivalent
Master's degree or equivalent
Doctorate degree
Other (please specify): $\qquad$
6. What is Caregiver 2's current level of education?

No schooling completed
Some school, did not attend high school
Some high school, not completed
High school graduate, with a diploma or the equivalent
Trade-technical-vocational training-Komvux

- Associate degree

Bachelor's degree or equivalent
Master's degree or equivalent
Doctorate degree
Other (please specify): $\qquad$
7. What year and month was your child born in? (e.g., 06/2009)
8. My child is...

Male
Female

- Prefer not to tell

Other (please specify): $\qquad$
9. What is the birth order of your child?

Firstborn and no siblings
Firstborn and has sibling(s)
Second-born/Third-born (or more)
Prefer not to say
Other (please specify): $\qquad$
10. When was your child diagnosed with ASD (year or age)?
11. Please choose any additional diagnoses of your child (you can choose multiple options)Intellectual Mental DisorderLearning difficultiesADHDMotor impairmentHearing impairmentVisual impairmentLanguage disorders or speech delayNo specific diagnosisOther (please specify): $\qquad$
12. Is your child nonverbal?

Yes

- No

No, but my child has a speech delay
Other (please specify): $\qquad$
13. In what country does your child live? (e.g., Sweden)
14. In what countries has your child lived before? (write them in order of living, e/g/, the first country will be the country of birth)
15. Do you plan to stay in your current country of residence?

Extremely unlikely
Unlikely
Neutral - don't know
Likely
Extremely Likely
16. Please specify what languages are used at the child's home (including sign languages)

Language 1 : $\qquad$
Language 2: $\qquad$
Language 3 : $\qquad$
Language 4: $\qquad$
Language 5: $\qquad$
Language 6: $\qquad$
17. How well does your child understand and communicate in each language used at home (in Q 16)?

More than age-appropriate
Age-appropriate
Less than age-appropriateMuch less than age-appropriate
Not at all

## filled for each language

18. Which language(s) do you speak at home and how often approximately (in \%)? (start with your native language) (e.g., Russian - $90 \%$, Swedish - 10\%)
NB: By "native" this means the language(s) you were raised to speak and understand from birth
19. Skip if not applicable Which language(s) does Guardian 2 speak at home and how often approximately (in \%)? (start with their native language)
(e.g., Russian - $90 \%$, Swedish $-10 \%$ )
20. Which language(s) do you mostly speak at home with...

Guardian 2: $\qquad$
Your child with ASD: $\qquad$
Other child(ren): $\qquad$
Other relative(s) living with you: $\qquad$
21. In which language(s) does your child...
(List the languages. N/A if not applicable)
Watch TV/Netflix/Disney+?
Read books?
Use mobile apps/devices?
Play video games?
Play boardgames?
22. Which types of alternative communication does your child use at home?
(you can choose multiple answers)
$\square$ Key Word SignsSign languageVisual schedulesPECSHigh-tech aided systemsCommunication appsOther (please specify): $\qquad$None of the above
23. In what languages are these types of alternative communication used? (e.g., PECS text in English).
Leave blank if not applicable
24. Please list all the languages your child can hear/see outside the home (including sign languages)
Language 1: $\qquad$
Language 2: $\qquad$
Language 3: $\qquad$
Language 4: $\qquad$
Language 5: $\qquad$
Language 6: $\qquad$
25. How well does your child understand and communicate in each language used outside the home (in Q24)?

More than age-appropriate
Age-appropriate
Less than age-appropriate
Much less than age-appropriate
Not at all
filled for each language

## 26. Please choose which educational organizations your child has either attended or is attending (including those in previously lived in countries)

You can choose multiple optionsMainstream kindergartenInclusive kindergartenKindergarten for children with special needsMainstream pre-schoolInclusive pre-schoolPre-school for children with special needsMainstream public schoolInclusive school or classAutistic support classrooms in a public schoolSpecial education class in a mainstream schoolSchool for children with special needsPrivate schoolMontessori or Waldorf schoolHomeschoolOther (please specify): $\qquad$None of the above

## 27. Which languages were/are used in school/kindergarten...

Write N/A if not applicable
Before your move to the current country of residence: $\qquad$
In your current country of residence: $\qquad$
28. Which types of alternative communication does your child use outside the home?

You can choose multiple answersKey Word SignsSign languageVisual schedulesPECSHigh-tech aided systemsCommunication appsOther (please specify): $\qquad$None of the above

```
29. In what languages are these types of alternative communication used? (e.g., PECS text in English)
Leave blank if not applicable
```

The next section of the questionnaire is going to ask you if you agree or disagree with some statements about your child with ASD.

Answering options in the questions 30-33:
Strongly disagree
Disagree
Neither agree or disagree
O Agree
Strongly agree
30. It is important for my child with ASD to be bilingual.
31. Answer this question if you have another child(ren) without ASD

It is important for my child(ren) without ASD to be bilingual.
32. With what statements do you agree?

Bilingualism is important for my child with ASD because it improves the following:
Communication with family members:
Communication with people in your country of residence:
Communication is school/kindergarten:
Life opportunities:
Future employment:

## 33. Answer this question if you have another child(ren) without ASD

With what statements do you agree?
Bilingualism is important for my child without ASD because it improves the following:
Communication with family members:
Communication with people in your country of residence:
Communication is school/kindergarten:
Life opportunities:
Future employment:
34. Have any of the following potential obstacles concerned you in regard to your child with ASD and learning other languages?
Answering options:

- Never

O Rarely
Occasionally
A moderate amount
O A great deal
Learning additional languages is too hard for my child:

There is not enough professional help for my child:
I cannot help my child learn another language:
I am afraid my child will become confused by two/more languages:
I do not have access to services that can help my child with bi/multilingualism:
My family and/or friends will not support my decision:
I am not sure if it is better to focus on one language:
Other (please specify):
35. What choice has your family made about the languages of your child with ASD?

I have chosen for my child to learn (speak) only their native language(s)
I have chosen for my child to learn (speak) only the language(s) of their current country of residence
I have chosen for my child to learn (speak) two or more languages
I have not decided yet

## 36. Please choose any strategies used in your family, if your child with ASD is learning an

 additional language(s)You can choose multiple options
$\square$ My child has a language tutorMy child takes special language classesMy child receives bilingual speech pathology supportWe teach the additional language(s)at home by ourselvesWe speak our native language(s) at home but outside of the home - we speak another language(s)
$\square$ We speak our native language(s) both at home and outside of home. The school is responsible for teaching the additional language(s)My child attends school/kindergarten in a second/another language(s)My child watches TV in both native and additional language(s)My child watches TV only in a second/additional language(s)My child watches TV only in their native language(s)We read books in both native and additional language(s)We read books only in a second/additional language(s)We read books only in our child's native language(s)
$\square$ Other (please specify) $\qquad$

The last part of the questionnaire is going to ask you about any received advice about your child's bi/multilingualism.
37. What professional views about bi/multilingualism of your child with ASD were you given at any time (if any)? Choose N/A if you are not in contact with this professional.
Note: One person - one language approach describes a situation when one caretaker speaks one language to a child, while another person uses a different language (e.g., a Swedish mother speaks Swedish, a German father - German to their child)

Answering options:Use the One Person-One Language approachUse different languages in different places (e.g., school, home)Raise your child bi-multilinguallyFocus on the language of your current country of residenceFocus on your native languageNo advice was givenN/A
Family Physician/Pediatrician:
Teacher:
Child's personal assistant/tutor:
Speech pathologist/Logoped:
Psychologist/Psychiatrist:
Social Worker:
Other (Please specify): $\qquad$
38. What other views about bi/multilingualism of your child with ASD did you receive? Answering options:Use the One Person-One Language approachUse different languages in different places (e.g., school, home)Raise your child bi-multilinguallyFocus on the language of your current country of residenceFocus on your native languageNo advice was givenN/A
Social Media:
Internet Forums:
Relatives:
Friends:
News Media:
Strangers:
Other (Please specify): $\qquad$
39. Were any of these questions either confusing or needing further explanation?
40. Do you have any suggestions on how to improve the questionnaire? Do you feel there is any information or further questions which could be included?

41 Would you agree to have a remote video or audio interview with me to discuss your family's language situation?

- Yes

O No
42. Please leave your email address if you answered 'yes' in the previous question or would like to receive the results of this research.

The Questionnaire is over. Thank you for your time! If you have any questions - please contact me at anme7664[at]student.su.se

## Appendix B

## Consent form

Informed Consent for Participants in research Projects Involving Human Subjects
Preliminary Project Title: "Family Language Policies in families of bilingual children on the autism spectrum"
Researcher: Anna Metreveli
Supervisor: Caroline Kerfoot

## 1. Purpose of the research

This research studies family language policies (FLP) affecting bilingual autistic children. It aims to determine what language and modality policies, practices, and ideologies are currently the most predominant ones in families of bilingual autistic children.

## 2. Procedures

You are invited to participate in up to two interviews that will take approximately one hour in a sum. The interviews will be held over Zoom and will be screen-recorded. You can choose to keep your camera turned-off for the duration of the interview. The recording of the interview will be transcribed and stored electronically. Participation in this research is completely voluntary and does not offer any monetary compensation.

## 3. Anonymity and Confidentiality

The recording will be transcribed by the researcher. Your name and any names you mention during the interview will not be connected with the recording. Written analysis and transcripts from your interview will be stored on a password-protected computer and not labelled with your name. Passages from the reflections and transcripts may be used in publications and related conferences, and presentations. Your confidentiality will be protected for this research. Any identifying information will be stored in a locked office.

## 4. Freedom to withdraw

At any time, you can choose to no longer participate, and you do not have to say why. If you no longer wish to participate before finishing the questionnaire - just stop and close the questionnaire. If you no longer wish to participate after filling out the questionnaire, you must notify the person in charge of the project (see contact details below). Withdrawal from this questionnaire will not imply any disadvantages or repercussions.
Any personal information that can be linked to you is considered personal data in accordance with the EU General Data Protection Regulation 2016/679 (GDPR). Stockholm University is the controller of this processing of personal data. According to the EU General Data Protection Regulation (GDPR) and national supplementary legislation, you have the right to withdraw your consent at any time, request access to your personal data, have your personal data rectified, erased, or restricted.

If you wish to invoke any of these rights, you should contact the researcher responsible for the project (see contact details below) or the data protection officer at Stockholm University (dso@su.se).
If you are dissatisfied with the way your personal data are processed, you have the right to file a complaint with the Swedish Authority for Privacy Protection (Integritetsskyddsmyndigheten). Information about this can be found on its website (imy.se).

The information will be used for research purposes only and nobody else except the researcher and their supervisor(s) will have access to them. Unauthorized persons will not be able to access the data. The data will be used for the thesis and related seminars and/or conferences. You will be able to partake of the results of the study by accessing the published thesis on Stockholm University DiVA platform on its website su.diva-portal.org. If you have any questions or concerns - please contact the researcher at anme7664@ student.su.se (or annametreveli@gmail.com) or her supervisor at caroline.kerfoot@biling.su.se.

## 5. Permission

## Please tick each box

| 1. I confirm that I have read and understand the Consent form for the study. I have |
| :--- | :--- | :--- |
| had the opportunity to consider the information, ask questions and have had |
| these answered satisfactorily. | .

$\overline{\text { Name of Participant }}$

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher /person taking the consent Date
Day/month/year

One copy of this form will be given to the participant and the original kept in the files of the researcher at Stockholm University

## Appendix C

## Interview 1 questions

## Questions to Liana (interviewed via Zoom, on 02.02.2022, in Russian)

1. Could you tell where come from? Where were you born?
2. What languages did you speak now and were speaking when growing up? Why were they chosen?
3. So you've actually been bilingual since childhood?
4. When did you move to (country of residence) and why?
5. How would you describe your current status in (country of residence)?
6. Let's discuss your boy. Could you tell a little bit about him and his diagnosis?
7. You skipped the question about your child's siblings. Does he have any?
8. Could you tell me about the biggest communication challenges with your child?
9. Overall, where would you place him on a scale of 0 to 5 , where 0 is "My child does not require additional support" and 5 is "My child requires a great amount of support"?
10. And so, in your questionnaire, you stated that it was very important for your child to be bilingual, but you also decided that it would be, that he would learn and speak only in English. Could you tell us more about your decision?
11. Has he ever been to Russia?
12. And what do you think could be the main difficulties in raising a bilingual child with autism?
13. How do you see the relative advantages or disadvantages of living in a bilingual home for autistic children?
14. How would you define bilingualism? To what extent do you think that autistic children can become bilingual?
15. You also answered that you use augmentative systems and visual schedules in English. Could you explain your decision to use only English for both?
16. What kind of augmentative devices do you use?
17. Who takes the biggest role in your child's language development and education in general?
18. How do you reach an agreement with your family? Do they participate in any decision making about your child's development?
19. You listed at least six languages that he hears outside the home in the questionnaire, which might not have been enough space. Could you tell me where and how often he hears them? Under what circumstances?
20. And public signs as well, right?
21. We've already started talking a little bit about his school. To what extent do you think your child's school supports your son's bilingualism?
22. What if it's French, let's say? What do you think, is it the same attitude or different?
23. What help and support would you like to receive from the schools, government or healthcare providers in (country of residence)?
24. The questionnaire also said that your son's speech therapist advised you to focus on the language of the country of your current residence. That is, in your case, English. How do you feel about such advice from specialists?
25. You have received a lot of contradicting advice from friends, relatives, social networks, forums, and strangers. What makes you take an advice or ignore it?
26. You've moved right into the next question about your plans for the future. How do you see them in terms of your child's education, bilingualism?
27. We are approaching my last question. Is there anything you would like to add? Something we haven't discussed so far, or you would like to ask me?

## Appendix D

## Interview 2 questions

## Questions to Alina (interviewed via Zoom, on 03.02.2022, in Russian).

1. Could you tell where you and your child's father come from?
2. What languages did you both speak now and were speaking when growing up? Why were they chosen?
3. How would you describe your status in Sweden?
4. Have you ever lived in a country other than Sweden?
5. Could you tell us a little bit about your child and his diagnosis?
6. So he was diagnosed here in Sweden?
7. Could you about the biggest communication issues you have right now, and how do you face them?
8. So from what I understand he needs quite a lot of support in speech development. And, if you could rate, let's say, his speech and overall development on a scale of 0 to 5 , where 0 is "he needs no support", and 5 - "he needs a significant amount of support. Where would you place him?
9. Do you think these indicators, do they improve over time, or do they stay in place?
10. What do you attribute these improvements to?
11. You stated on the questionnaire that it is very important for your child to be bilingual. You decided that he would learn and speak two or more languages. Can you tell us more about these decisions? What motivated you to make this decision?
12. What do you think are the main difficulties or positive aspects of raising an autistic child bilingually?
13. And so it looks like... Just to sum up the language in your family, that your family speaks two main languages, as I understood from the questionnaire: Swedish and Russian. Could you tell a little bit more about it and tell how you feel about it... Because in Sweden, English is a very widespread language, and it has such a socially high position. How do you still feel about English in this whole picture?
14. In general, what definition would you give of "bilingualism"? And to what extent do you think autistic children can become bilingual?
15. Do you think this dynamic will continue, that his vocabulary in Swedish will continue to grow?
16. You said the Swedish grandmother is in Stockholm. And with your family in Russia... Do you have any contact? Do you go there?
17. You also mentioned that your child watches TV, Netflix; you read him books in Russian and Swedish. Could you tell more about that, too. Which ones does he like to watch and listen to more?
18. And at school, how do they use them? In kindergarten, sorry.
19. Who do you think then plays the biggest role in your son's language development and education in general in your family?
20. You also answered that your son hears mostly Swedish and Russian outside the home. What other languages do you think he hears? On the streets, for example.
21. I got the impression from your questionnaire that you are a little concerned about the amount of professional support your son receives here in Sweden. What kind of help and support would you like to receive from the state, the school, the doctors?
22. Do you get any advice or help at the Rehabilitation Center?
23. In the questionnaire, you noted that she recommended that you use the "one person, one language" approach, that is, that you speak Russian, and his dad speaks Swedish. How, how much do you agree with this approach? How do you feel about it?
24. You also get this kind of similar advice from social media, on Internet forums, from people you know and strangers, among others. What makes you follow the advice, what makes you ignore it? What do you pay attention to?
25. What are your plans for the future? Regarding the child and his bilingualism?

26 . Is there anything you would like to add or ask me?

## Appendix E

## Interview 3 questions

## Questions to Rita (interviewed via Zoom, on 03.02.2022, in Russian)

1. Could you tell where you and your child's father come from?
2. What languages did you both speak now and were speaking when growing up? Why were they chosen?
3. You moved to Germany. Could you tell me when and why?
4. How would you describe your status in Germany?
5. Have you ever lived in a country other than Germany. And if so, which ones?
6. Tell me a little about your child and their diagnosis.
7. On the questionnaire you answered that your son has no siblings. Now you mentioned that you have a daughter?
8. Are your daughters neurotypical?
9. Could you tell me about the biggest communication challenges with your child that you are having now?
10. So from what you've said, it seems that your child has a small developmental and speech delay. Overall, where would you place them on a scale of 0 to 5 , where 0 is "My child does not require additional support" and 5 is "My child requires a great amount of support"?
11. So, in the questionnaire you answered that it was very important for your child to be bilingual and decided that he would learn and speak two or more languages. Could you tell what motivated you to make that decision?
12. Are there any challenges of raising your autistic child bilingually?
13. It seemed to me that at least five languages are used in your home. Judging from the questionnaire. And your child, too, according to the questionnaire, speaks at least three of them to a greater or lesser degree. Could you tell more about that? How does your family communicate in general?
14. What do you see as the benefits of living in a bilingual environment for an autistic child?
15. Has your child visited grandparents in other countries?
16. Are you planning to visit your child's grandparents?
17. How would you define "bilingualism" at all? What does it mean to you? And to what extent do you think an autistic child can become bilingual?
18. You skipped the question about watching TV in other languages. Could you tell me more about whether your child watches TV?
19. What language does your neurotypical daughter watch cartoons in?
20. Could you tell me; on the basis of what language do you use gestures? That is, how often and under what circumstances do you use it?
21. It sounds like you have a very large and multicultural family, and you have other relatives living with you, as I understand from the answers. Who do you think plays the biggest role in your child's language development and your family's education?
22. How do you reach an agreement with your family when making decisions about your child's language development and education?
23. So, am I correct in assuming that you also wanted him to speak Arabic himself, because his German is, shall we say, not native and not, roughly speaking, grammatically correct?
24. You also answered that the child mostly hears only German outside the home. And it is the only language he hears outside the home. Could you tell me where and how often he hears it?
25. You also answered that your child does not use any alternative communication outside the home. So now we understand that he doesn't go to school. But when you will be choosing school or day care. Will you be expecting any support in your child's bilingualism?
26. What kind of help and support would you like to see from the state, from schools, from doctors. In general, not only about bilingualism, but about your child's development in general?
27. How do you feel about these expert views?
28. So, in general, you agree with the advice of experts, to separate the languages in the family? 29. You also got a lot of contradictory advice from relatives, Internet forums, social networks. How to raise a child in a bilingual environment. What makes you, shall we say, follow the advice or ignore it?
29. Do your relatives from both sides share the same view? Or do they have their own view on the situation?
30. What are your future plans for your child's education and bilingualism?
31. Is there anything you would like to add? If there is something I haven't asked you or you have forgotten to say and ask me?

## Appendix F

## Interview 4 questions

## Questions to Marina (interviewed via Zoom, on 04.02.2022, in Russian)

1. Could you tell where you and your child's father come from?
2. What languages do you and your son's father speak?
3. When did you move to Spain?
4. How would you describe your status in Spain now?
5. And what would you say is the more prevalent dialect where you live?
6. Could you tell a little bit about your child and his diagnosis?
7. In general, what would you say are the biggest challenges in communication right now?
8. Why do you think it took so long to receive a diagnosis?
9. So from what you have said, I understand that your main difficulties are with motivation and with sensory integration. So, if you could characterize your child's development, including language development, on a scale of 0 to 5 , where 0 is "requires no extra help or support at all" and 5 is "requires a lot of support", where would you put him?
10. You said in the questionnaire, as I understood it, that the main language you use at home is Russian. Could you tell me more about this decision? Why did you decide to focus only on Russian?
11. What language do the children use to communicate with each other?
12. As for the language outside the home. I understood from the questionnaire that he hears mostly Castellano and Valenciano and you also mentioned English. Could you tell me more about what is going on?
13. But if someone on the street addresses him in Castellano or Valenciano, will he answer in the same language or not?
14. And you also noted on the questionnaire that you neither agree nor disagree with the statement "bilingualism is important to my child". However, you also mentioned that it is more important for your neurotypical children. Could you elaborate on that?
15. So, do I understand you correctly: you give priority to Spanish for now? And to Russian, if it works out?
16. What definition would you give to the term "bilingualism"? What is bilingualism to you?
17. To what extent do you think autistic children are capable of being bilingual?
18. Many people who live in Spain complain that compared to Russia, the number of specialists and the quality are much worse. What do you think about that?
19. You said you only speak Russian at home, and you also mentioned on your questionnaire that he watches TV, Netflix. Is that the only thing he does at home in Spanish?
20. Who do you think plays the biggest role in your child's language development and in making decisions about developmental activities, including language?
21. How do you reach agreement with the husband, with the family about bilingualism?
22. And your parents, are they involved in the decisions?
23. And as for the school, how are things there? As I understand it, is it Castellano and Valenciano? Do they support your child's bilingualism at all?
24. Have you thought about living in a region where there is only one Castellano?
25. Going back to the topic of government. What kind of help and support would you like to receive from the government/schools/medical institutions?
26. You stated that your son's teacher, tutor, and pediatrician advised you to focus only on the language of your country of residence. How did that make you feel?
27. Do you plan to visit grandparents in the summer?
28. So you're only talking to grandparents on Zoom so far?
29. And what about your son, does he participate in communication with grandparents?
30. You skipped the question about advice from social media, from relatives, strangers, and others. How do you feel about such advice? What makes you follow or disregard advice?
31. You've already mentioned a little bit your plans for the future. What are your plans for the future when it comes to your child's education and bilingualism?
32. Regarding future plans for bilingualism: will there be any new languages introduced in his school?
33. Is there anything you would like to add or ask?

## Appendix G

## Interview 5 questions

## Questions to Nina (interviewed via Zoom, on 09.02.2022, in Russian)

1. Could you tell where you and your child's father come from?
2. And in the family, who is there?
3. What languages, then, did you and your husband speak when you were growing up?
4. Could you tell a little bit more about your autistic child. Does he have an official diagnosis, or not?
5. As I understand it, he has a more than age-appropriate language development. But do you encounter any difficulties in communication?
6 . From what you have said, as I understand it, the main difficulties are still related to social skills. That is, something is acceptable to say something not acceptable? Some, some boundaries...
6. And what about schools, do you think they support the bilingualism of children?
7. Judging from your questionnaire it is clear, as well as from your story now, that the main languages at home are Russian and Hebrew?
8. Okay. So, outside the house he hears mostly Hebrew and Russian, right?
9. And in the questionnaire, both the question about your autistic child and your other children, you chose to say that bilingualism is important for my child?
10. In the questionnaire about potential barriers to learning additional languages. You answered "in different ways in different periods". Could you clarify that answer a little bit?
11. You answered, accordingly, that you have decided to raise your son in two main languages. Are there any difficulties in such an upbringing?
12. Okay. And what do you see as the advantages or disadvantages of living in a bilingual and multilingual environment for an autistic child?
13. What definition would you give to the concept of bilingualism, multilingualism?
14. I also get the impression that you use one language in one place. That is, when somewhere on the street, Hebrew is likely to be...
15. Who do you think plays the biggest role in your family in his development and language decisions?
16. Do you keep in touch with his grandparents and relatives?
17. What kind of help, support would you like to receive from the state, the school?
18. You answered that most professionals had advised you to raise your child in two languages?
19. What do you think of the advice about bilingualism and the development of autistic children in general that you see on social networks, on forums somewhere?
20. What are your plans for the future in relation to your child's multilingualism?
21. If there is anything you would like to add, ask me, or comment about anything?

## Appendix H

## Interview 6 questions

## Questions to Sofia (interviewed via Zoom, on 10.02.2022, in Russian)

1. Could you tell where you and your child's father come from?
2. What languages do you speak? Besides Russian and Spanish with the father.
3. What languages did you speak in your family as children with your parents and siblings?
4. Could you tell me when you moved to Sweden and why, and whether you plan to stay here.
5. So how would you describe your status in Sweden for both of you now?
6. Could you tell a little bit about your child, his diagnosis?
7. From what you have said, it seemed to me that the main difficulties are precisely in speaking. It's about being understood. So, if you could characterize your child's development, including language development, on a scale of 0 to 5 , where 0 is "requires no extra help or support at all" and 5 is "requires a lot of support", where would you put him?
8. It looks like your native languages are Russian, Swedish, and Spanish. And in the survey you mentioned that you only use Swedish when you receive guests.
9. And outside the home, too, it turns out that he hears mostly Swedish, Spanish, and Russian. Could you tell more: where and how often?
10. Do you travel home yourself? To Estonia or Peru.
11. During the pandemic, did you probably only use Skype or zoom to talk to his grandmother?
12. You also noted that you only read books to him in Russian, but you watch TV, Netflix, do some other activities in Swedish and in Russian. Why only books in Russian?
13. Does his dad read books?
14. And you also completely agreed with the statement that bilingualism is important for your autistic child, and also for your daughter, who is a neurotypical child. Could you elaborate on those decisions as to why you think it's important?
15. For you in general, what is bilingualism? What definition would you give?
16. In the question about possible obstacles that might concern you about your autistic child's bilingualism, you didn't choose anything. How would you explain this? You don't see any obstacles?
17. What do you think in general: do you get enough help or would you like to get some more help from the state, from schools, from doctors?
18. And what languages do they speak at school?
19. Do you think they support his bilingualism? By providing material in other languages or?
20. By the way, I wonder which subject you will choose as his mother tongue at Swedish school for him: Spanish or Russian?
21. What do you see as the relative advantages of living in a bilingual home environment for children in mixed marriages in general?
22. Yes. So, from what you have told me, I see that you use the "one parent, one language" policy in your family? The fact that you speak Russian...
23. How did you initially decide to do this in your family? Or did someone advise you to do it?
24. Did your relatives share your view?
25. And how do they generally relate to the linguistic situation?
26. And you also answered that you don't use any augmentative systems or visual scheduling at home. Have you ever used one or considered starting?
27. And at school, are all these visual schedules in Swedish, I guess, or no language at all?
28. In your family, who do you think makes the major decisions about his development and language development in general?
29. And there, too, was a question about advice from social networks, Internet forums, strangers, and acquaintances. You answered that you don't get any advice. Could you tell me more about that. Do you not consider advice from such sources?
30. What are your future plans for your son's education and development?
31. Last question: if there's anything you'd like to add that you don't think we've discussed. Or ask me something?

## Appendix I

## Interview 7 questions

## Questions to Isabella (interviewed via FaceTime, on 10.02.2022, in English)

1. What languages do you and your son's father speak right now, and we're speaking when you were growing up?
2. You have mentioned that you used to live in the US. Could you tell more about this period of your life?
3. And your husband's home language was only English?
4. So how would you describe your status now in Sweden?
5. Could you tell me a little bit more about your son and his diagnosis?
6. Is he (autistic son) still living with you?
7. And you also mentioned that your son has siblings. Could you tell me a little bit more about them?
8. What language do they (children) speak and did they speak?
9. Why did you decide not to use Portuguese with your kids if you don't mind me asking?
10. Right. You also mentioned many languages that he hears outside of and heard outside of his home. So like Swedish, English, Polish, Spanish and French. Could you elaborate a little bit more? 11. You've also answered that he reads books and watches TV, Netflix platforms like that, mostly in English and Swedish. Was it the same when he was growing up?
11. I've noticed that English has gained more important status in Sweden in the recent decade or even more. How would you say that has influenced the language you use in your family and his language?
12. You also mentioned that you agree strongly that bilingualism is important both for your autistic kid and for your neurotypical daughter. Could you tell why?
13. Do they (your children) have children?
14. There was a question about potential obstacles, and I know that your son is grown up right now, but when he was growing up. Have you ever noticed any obstacles in raising him bilingually or anything that made you think "Oh, that's tricky", or that seems to be more complicated?
15. It seems to me that your daughter has English as a dominant language from what you've said and your son is kind of $50-50$, right? Have you ever talked to him? Like, does he see any difficulties in maintaining his bilingualism right now as an adult? Or is it very natural to him?
16. And in his conversational speech, does he code-switch a lot of meaning that he would use, for example, Swedish words when he's speaking English with you or vice versa?
17. When they were growing up, were they in contact with their grandparents? What language were they speaking with them, especially with your parents?
18. I always ask my participants because they give wonderful definitions, each one of them. How would you define bilingualism?
19. Ok, and when your kids were growing up, who do you think made the most, you know, was responsible for decision making when it comes to language education? Who made all the decisions when it came to language and education in your family when your kids were growing up?
20. And to your family members and your parents, your mom, when they were growing up, did she tell you about her view about that?
21. Do you think you received any kind of support in terms of bilingualism back then, from the government, from schools, or? Especially in comparison to the U.S., for example?
22. So did you have any particular plans about future when you were raising your son, like what were your plans for then and seeing how he's adulting right now? Do you think... Something you regret, for example, or are happy about something? Some choices that you've made.
23. The last question is, is there anything you would like to add that we haven't discussed, and you think it's important or ask me?

## Appendix J

## Interview 8 questions

## Questions to Konstantin (interviewed via Zoom, on 11.02.2022, in Russian)

1. Could you tell where you are from and where you were born?
2. What languages do you speak, and did you speak as a child? You and the child's mother?
3. What languages did you learn at school?
4. How did you end up in Sweden? How would you describe your status in Sweden?
5. Are you planning to stay or not?
6. Could you tell a little bit more about him (the child) and his diagnosis?
7. And you also mentioned that your son has a brother or a sister. Could you tell me more about that?
8. Could you talk about the biggest communication problems you have now and have had?
9. How do you communicate now?
10. From what you've told me it seems to me that the child needs extra support in terms of communication. So, if you could characterize your child's development, including language development, on a scale of 0 to 5 , where 0 is "requires no extra help or support at all" and 5 is "requires a lot of support", where would you put him?
11. It seems that the home languages spoken in your family are Russian, English, and Swedish. Could you tell me more about why this is the case?
12. So you use English at work?
13. That is, how do you think in general, when he watches cartoons and chooses (languages) does he understand what a foreign language is?
14. Does the assistant mostly communicate with him in Russian?
15. It appears that you have a neutral view about the statement that 'bilingualism is important for my autistic child' but have chosen that bilingualism is important for your neurotypical child, i.e., your daughter. Would you be able to comment in any way?
16. In the question about potential obstacles you might be concerned about your autistic child's bilingualism - I get the impression that your biggest concern is access to the services you might be receiving for your child?
17. You generally answered that you've decided to raise your autistic child bilingually. Given that he is nonverbal and doesn't speak at all, how do you envision this going forward?
18. In an (communication) app, which language do you think would be a good idea to use?
19. What about the school? What types of alternative communication? Since from the questionnaire I understand the school also uses alternative communication and a visual schedule. 20. You also noted that the school uses what's called "key word signs". Do you use them at all with your child at school?
20. Do you also use gestures at home?
21. In general, what do you think are the relative advantages or disadvantages of living in a bilingual or multilingual environment for an autistic child?
22. How would you define the term "bilingualism"?
23. So you are now living in another country. Do you consider yourself bilingual?
24. You also mentioned that your wife makes most of the decisions about language. Is this true? How do you and your family in Russia discuss the language situation in general, any views you may have heard?
25. We haven't spoken about your and your wife's parents. Are they somehow involved in these decisions and maybe have a view?
26. And before that, did you go to Russia?
27. So now you're communicating remotely, through Zoom, via Skype (with grandparents)?
28. How do your parents and your wife's parents perceive the language situation when your daughter, for example, talks to them? That is, do they feel living abroad is affecting native language?
29. As for your son, how did they (family) take your decision to be bilingual?
30. What kind of help would you ideally like to receive from the state, from education, health care in the country of residence? In terms of development, including language development.
31. Based on your questionnaire, you have received a lot of conflicting advice from specialists about your son's bilingualism. Why do you think this happened and how do you choose which advice to follow and which not to?
32. If we're talking about advice from social networks, Internet forums and online groups... As I understood from your questionnaire there is also a huge amount of contradictory advice you have received. Do you use the same logic?
33. What are your plans for the future? Regarding your autistic child and his speech development, bilingualism, and development in general.
34. Is there anything you would like to add that you feel we haven't discussed that is important to discuss and anything you would like to ask me after filling out the questionnaire, this interview?

## Appendix K

## Interview 9 questions

## Questions to Vera (interviewed via Zoom, on 21.02.2022, in Russian)

1. Could you tell me where you and your child's father are from?
2. What languages do you speak?
3. What language does your husband speak?
4. How do they (family) communicate with your children, in what language?
5. What languages did you both speak when you were growing up? If you can be more specific, what did you learn at school?
6. And what countries did you and your husband live in before?
7. Could you tell me a little bit about your son's diagnosis?
8. And could you then tell about the biggest communication issues that you're having right now?
9. Is the speech therapist in French?
10. So in general, how would you rate him now on a scale of zero to five, where zero is "my child needs no extra support at all", and five is "my child needs a lot of support"?
11. And on the questionnaire, you also said that the home languages in your family are Russian, French, Arabic, Lebanese, and English?
12. What language do children use to communicate with each other?
13. What languages are used outside of school, on the street, maybe some activities?
14. In the questionnaire you take a positive view of bilingualism for both children. Both for the autistic child and the neurotypical child. Could you elaborate more on those decisions?
15. Who did you hear such comments (about the languages) from?
16. In the questionnaire, there was also a question about potential barriers that you might be concerned about with your autistic child's bilingualism. And it sounded to me like you were most concerned about not having access to services that could help your child?
17. And many people from Ukraine, from Russia, who live abroad, often receive additional services, let's say, remotely from home countries, what about you?
18. And about the books, in the questionnaire you answered that you mostly read in French?
19. And you answered that you decided to raise your child in two languages. In your case, even more. What do you think are the difficulties in such an upbringing, are there any?
20. How does he communicate with your relatives?
21. So we've talked a little bit about some of these negative aspects. And what about the benefits, the positive aspects of living in a multilingual environment for autistic children, do you see any benefits, so to speak?
22. How would you define "bilingualism" in general. What definition would you give?
23. Also from the questionnaire and from your answers to the questions now, I understand that you use the "one parent, one language" approach at home. That you speak Russian, your husband speaks Arabic. Could you tell me more about that as well? Have you received any advice on how to proceed with it?
24. You also wrote on your questionnaire that you use gestures at home and that you use additional gestures at school?
25. And so who do you think plays the biggest role in your family in your child's language development? Education in general.
26. And you've mentioned a little bit that originally your husband's family advised you to switch to Arabic. How is it now, when the child speaks?
27. But now that we're talking about medics. What kind of help and support would you like to get from the government, from schools, from medical institutions in Lebanon?
28. I got the impression that you get and have received a lot of conflicting advice from professionals. How do you, then, choose? What advice do I listen to? And which ones I don't.
29. Going back to the advice. There's still a lot of contradictory advice from social networks and Internet forums, too. Also, what makes you follow or not to follow this or that advice?
30. You've already touched a little on your future plans for languages. What are your plans for the future in general?
31. Is there anything you'd like to add that we haven't discussed? Or to ask me?

## Appendix L

## Transcript of interview 6 with Sofia

1. Не могли бы вы сказать откуда вы и отец вашего ребёнка родом?

Sofia: Я из Эстонии. Русскоговорящие. Мой родной язык русский. Отец ребёнка из Перу. Его родной язык испанский.
2. Понятно. И тогда на каких языках вы говорите? Помимо русского и испанского с отцом.
Sofia: В смысле?
Sofia: Вообще мы говорим. Ну как, ну шведский конечно же. Потом у отца ребёнка. Ну конечно шведский он говорит, и на английском. Но он считает, что не очень. Что он не очень силен в английском. Я говорю. Так как я из Эстонии. У меня родной язык русский, но эстонский я тоже изучала. Хотя давно его уже не использую, но все-таки говорить пока могу. Полностью не забыло. Но английский, шведский, конечно же, потом испанский, на котором мы дома общаемся вместе. Папа ребёнка. Итальянский изучала. Ну одно время долго. Одно время часто использовала, сейчас меньше на нем говорю. Сейчас больше на испанском говорю каждый день. Одно время использовала итальянский намного больше и читала на нем много. Потом ещё языки, которые я изучала и на которых. Ну не то, чтобы говорю, но пробовала читать, кое-что понимаю. Например, на датском пробовала читать, на норвежском пробовала читать, на французском пробовала читать. Сейчас вот пытаюсь освоить хоть немножечко арабский. Вроде алфавит прошла, хотя буквы ещё путаю. (Понятно) В общем так.
3. В детстве получается в семьях ваших $\mathbf{c}$ родителями $\mathbf{c}$ братьями сёстрами на каких языках вы разговаривали в семье?
Sofia: По-русски и по-испански.
Anna: Понятно.

1. Could you tell where you and your child's father come from?

Sofia: I'm from Estonia. Russian speakers. My native language is Russian. The father of the child is from Peru. His native language is Spanish.
2. I see. And then what languages do you speak? Besides Russian and Spanish with the father.
Sofia: What do you mean?
Sofia: Actually, we're speaking. Well, how, well Swedish of course. Then the father of the child. Well of course he speaks Swedish, and English. But he doesn't think he's very good at it. That he's not very good at English. I do. Because I'm from Estonia. My native language is Russian, but I also studied Estonian. Although I haven't used it for a long time, I can still speak it. I haven't forgotten it completely. But English, Swedish, of course, then Spanish, which we speak at home together. The child's dad. Italian - I studied. Well for a long time, at one time. I used to use it a lot at one time, now I speak it less. Now I speak more Spanish every day. At one time used Italian a lot more and read a lot. Then other languages that I studied and in which... Not so much speaking, but I tried to read, I understand some things. For example, I tried to read in Danish, I tried to read in Norwegian and I tried to read in French. Now I'm trying to learn at least a little bit of Arabic. I think I got through the alphabet, although I still mix up the letters. (I see) Anyway, that's it.
3. What languages did you speak in your family as children with your parents and siblings?

Sofia: In Russian and Spanish.
Anna: I see
4. Не могли бы что сказать, когда вы переехали в Швецию и почему и планируете ли оставаться здесь?
Sofia: Я приехала в Швецию в 95 году. И причины были две: во-первых, собиралась изучать скандинавские языки. Во-вторых, был молодой человек в Упсале. Потом. Ой господи. Это вещи падают.
Anna: Ничего страшного.
Sofia: Обувь раскидывают. (пауза)
Sofia: Извините. Ну вот и я приехала я училась в университете в Упсале. Изучала скандинавские языки. Ну вот, а после этого осталась. Это. Уже надолго. Конечно, трудно загадывать. Никогда не говори никогда. Не знаешь, никогда не знаешь где окажешься через 10 лет, но пока уезжать никуда не собираюсь. Тем более что дети здесь в школу ходят.

## 5. То есть как бы вы сейчас описали ваш статус в Швеции обоих?

Sofia: Ну, у меня шведское гражданство, давно здесь живу. Пока не, пока переезжать не планирую. Когда-нибудь ну конечно может когда выйдешь на пенсию, мало ли куда захочется.
Anna: Но на юг (смех).
Sofia: Да.
Anna: Хорошо.
6. Расскажите тогда немножко о
вашем ребёнке, его диагнозе.

Sofia: Ну детей у меня двое - один без диагноза, другой с диагнозом. И с диагнозом младший, ему 9 лет. Старшей будет 12 в марте. И у младшего у него диагноз аутизм. И как раз вот. Сложности, которые мы заметили, когда ещё... То есть ещё до того, как ему поставили диагноз, когда ему было... Года два-три, мы заметили, что он очень мало говорит. То есть он говорил отдельные слова. Его было очень трудно понять, он говорил очень нечётко. У него, например, все согласные у него превращались в к-г и х. И причём говорил он в основном дома отдельные слова по-русски, по-испански. А в садике практически молчал. И вот из-за этого и ещё из-за некоторых. Признаков, того, что у него какие-то трудности нас направили на обследование, и он получил диагноз аутизм когда ему было 4 года, только, только исполнилось четыре года. И в то время он очень мало
4. Could you tell me when you moved to Sweden and why, and whether you plan to stay here?
Sofia: I came to Sweden in '95. And there were two reasons: first, I was going to study Scandinavian languages. Secondly, I had a boyfriend in Uppsala. Then. Oh my goodness. Things are falling down.

Anna: That's okay.
Sofia: The shoes are scattered. (pause)
Sofia: I'm sorry. So here I am, I went to university in Uppsala. I studied Scandinavian languages. So, after that I stayed. That. For a long time. Of course, it's hard to know. Never say never. You never know, you never know where you'll be in ten years, but I'm not going anywhere for now. Especially since the kids go to school here.

## 5. So how would you describe your status in Sweden for both of you now?

Sofia: Well, I have Swedish citizenship, I've lived here for a long time. Not yet, I don't plan to move yet. Someday, of course, maybe when you retire, you don't know where you want to go.
Anna: But to the south (laughing).
Sofia: Yes.
Anna: Good.
6. Could you tell a little bit about your child, his diagnosis?
Sofia: Well, I have two children - one without a diagnosis and one with a diagnosis. And the younger one is diagnosed, he's 9 years old. The older one will be 12 in March. And the youngest is diagnosed with autism. And just like that. The difficulties that we noticed when we were still... I mean, even before he was diagnosed, when he was... About two or three years old, we noticed that he spoke very little. I mean, he spoke single words. It was very difficult to understand him, he spoke very vaguely. For example, he had all his consonants turned into k-g and h. And he spoke mostly separate words in Russian and Spanish at home. And in kindergarten he was practically silent. And because of that and some other things. Signs that he had some kind of difficulties, we were sent for a check-up, and he was diagnosed with autism when he was 4 years old, just, just turned 4 years old. And at that time he spoke very little, almost only individual words. And he

говорил, практически только отдельные слова. И его было очень трудно понять. Но вот как раз именно в тот период, когда он проходил обследование, произошло что-то интересное. У нас есть, у него есть старшая сестра - на два года старше, на два с половиной. И она... У неё как раз была у неё с речью было всегда очень хорошо, было у неё, она очень рано заговорила. Она в полтора года уже много слов говорила и на русском, и на шведском, и на испанском. У неё, в общем, очень хорошо шло это. Очень быстро шло речевой развитие, словарный запас рос. И сейчас она говорит, читает и пишет уже на четырёх языках. Потому что ещё и английский добавился. Ну вот. А у (имя) мы заметили, что разница была очень большая. Хотя, конечно, сравнивать детей нельзя, но у него и по сравнению с обычными детьми его возраста была большая разница. Но, вот когда ему было 4 года как раз. В то время, когда он проходил обследование, как раз ему должно было исполниться четыре. Мы заметили, что он интересуется буквами. Он стал смотреть видеоролики, по которым старшая сестра когда-то училась читать. То есть он их сам нашёл когда-то мы их качали и сохранили на компьютере. Он сам стал их находить, просить, чтобы поставить, сам стал их смотреть. И там были буквы. Там, вопервых, были видеоролики о русском алфавите. Там были... Видео, такие мультфильмы, где буквы складываются в слоги и читаются. Вот такие вот, обучающие. И ему это очень нравилось, и он их смотрел. И я ещё заметила, что он начал, начал на улице узнавать слова на вывесках. На табличках, мог посмотреть и сказать, что написано. И вот я проверила как-то, оказалось, что он знает весь русский алфавит. То есть он по этим видеороликам выучил весь русский алфавит. Он мог назвать буквы в алфавитном порядке. Он мог сказать, как они пишутся, он мог их сам написать. А в детском саду мне сказали, что он и шведский алфавит знает. И вот одно время это была какой-то, это было одно из его любимых занятий. Просто сидеть и писать. Он мог сидеть просто. Писать на бумаге русский алфавит
was very difficult to understand. But it was just during that period when he was being examined that something interesting happened. We have, he has an older sister two years older, two and a half years. And she... She just had, her speech was always very good, she had it, she spoke very early. At the age of one and a half, she already spoke a lot of words in Russian, in Swedish, and in Spanish. She, in general, was very good at it. The speech development was very fast, the vocabulary was growing. And now she speaks, reads and writes four languages already. Because she added English as well. There you go. And with (name) we noticed that the difference was very big. Although, of course, you cannot compare children, but he had a big difference compared to other children of his age. But, here's when he was four years old at that time. At the time he was being examined, he was just about to turn four. We noticed that he was interested in letters. He started watching videos that his older sister used to learn to read. That is, he found them himself once we downloaded them and saved them on the computer. He started finding them himself, asking to play them, started watching them himself. And there were letters. There were, first of all, videos about the Russian alphabet. There were... Videos, such cartoons, where the letters are put into syllables and are read. Just like that, educational. And he really liked that, and he watched them. And I also noticed that he started, he started recognizing words on signs on the street. On signs, he could look and say what was written. And so I checked once, it turned out that he knows the whole Russian alphabet. That is, he learned the entire Russian alphabet from these videos. He could name the letters in alphabetical order. He could tell how they were written, he could write them himself. And I was told in kindergarten that he knew the Swedish alphabet, too. And so at one time it was some, it was one of his favorite things to do. Just sitting and writing. He could just sit. Writing the Russian alphabet on paper simply. And now to draw out the letters beautifully. To be like that. Then, he would write some of his favorite words. At one time we had. It was written everywhere: on his drawings, on the floor, on the wall. Then he wrote with his finger on the foggy glass, he wrote with crayons, he

просто. Причём сейчас красиво вырисовывать буквы. Чтобы были такие. Потом, он писал какие-то свои любимые слова. Одно время у нас было. Написано везде: на его рисунках, на полу, на стенке было написано. Потом он писал пальцем на запотевшем стекле, писал мелками, писал палочкой на снегу, где только не писал. В детском саду просто вставал к стенке и писал пальцем. И вот часто писал какие-то свои особенные и любимые слова. Одно время у нас почему-то «ежик» был. Не знаю почему. Потом «вертолёт». Но вертолёт - это вообще очень такое. У него. Сложные отношения с вертолётом. Он то ли его боится, то ли он его манит как-то.
Anna: Угу.
Sofia: Ну вот. И. Вот одно время он все время писал отдельные слова какие-то свои любимые. Что у него ещё было? «Автобус» он писал, в общем такое вот. Где-то вот в районе рождества, в конце, в конце... Какой это год был? Когда ему... Он ещё в школу не ходил. Как раз за несколько, где-то примерно за месяц до того, как умер Ингвар Кампрад.
Anna: ((смех))
Sofia: Почему я это запомнила. Он почему-то вдруг начал везде писать Икеа, Икеа. Рисовать какие-то здания, писать Икея, и рисовать вывеску Икея. И вот где-то через несколько недель сообщают, что умер Ингвар Кампрад. Правда жутковато стало. Ну вот, и, в связи с этим вот он почему-то нам начал намного более чётко говорить. То есть ему письмо помогло понять, как произносятся слова. То есть после того, как он начал писать, он начал их намного более чётко выговорить. И вот как-то это быстро пошло. Он сам научился читать, понял, как складываются слова в слоге. И я ему тогда купила игры и магнитные буквы. Он стоял и экспериментировал с магнитной буквами, пытался две согласные сложить вместе и прочитать, что получается. Потом на вывеске, на улице он читал, на табличках читал. Все станции метро. Мог прочитать, например, вот там, где карта метро - он мог прочитать все названия всех станций. И вот, в связи с этим его речь
wrote with a stick on the snow, he wrote everywhere. In kindergarten he just stood up against the wall and wrote with his finger. And he would often write some of his special and favorite words. At one time we had a "hedgehog" for some reason. I don't know why. Then "helicopter". But "helicopter" was very special. He has. He has a complicated relationship with a helicopter. He's either afraid of it, or he's attracted to it somehow.

Anna: Uh-huh.
Sofia: That's that. And. At one time he kept writing individual words of some of his favorite things. What else did he have? He used to write "bus", stuff like that. Somewhere around Christmas, at the end, at the end... What year was that? When he... He wasn't in school yet. Just a few, about a month before Ingvar Kamprad died.

Anna: ((laughing))
Sofia: Why did I remember that. For some reason he suddenly started writing everywhere - Ikea, Ikea. Drawing some buildings, writing Ikea, and drawing an Ikea sign. And then about a few weeks later, it was reported that Ingvar Kamprad had died. It got really creepy. So he started to speak much more clearly for some reason. That is, writing helped him understand how words are pronounced. That is, after he began to write, he began to pronounce them much more clearly. And somehow it moved on quickly. He learned to read on his own, he understood how words are put together in a syllable. And I bought him games and magnetic letters then. He stood and experimented with magnetic letters, tried to put two consonants together and read what came out. Then on the sign, on the street he would read, on the signs he would read. All the subway stations. He could read, for example, over there, where the subway map, he could read all the names of all the stations. And so, in connection with this, his speech began to develop much faster. I mean, now he still talks like... Like a little

начала развиваться намного быстрее. То есть, сейчас он до сих пор говорит как... Как маленький ещё. Он ещё не умеет. То есть, для него основная трудность - это выражаться так, чтобы его поняли. Говорить связно. Грамотно строить предложения. Рассказывать о чем-то связно. То есть, когда он начинает о чемто говорить - это получается очень часто, получается какие-то обрывочные короткие фразы. То есть нужно очень часто, надо понимать, что он хочет сказать. Чтобы понять его. И вот этому мы сейчас учимся. Например, мы... Одно время много занимались с картинками. Он очень любит, когда фотографируют. То, что он делает, знакомые предметы. Например, когда мы на прогулке, то мы часто фотографируем: его, и то, что он делает и то, что мы видим, игрушки тоже. Он, например сидит и играет, и сам просит, чтобы я сфотографировала его, когда он играет. И после этого он эти фотографии рассматривает. И мы это используем, чтобы поговорить на эту тему о том, что что произошло, что он делал. Что он видел. И ещё у нас есть дневник. Мы пишем вместе. Когда мы, например, куда-то ходили вместе. Он сам напоминает, чтобы мы записали в тетрадки. Я пишу то, что мы делали. То есть это получается, как бы короткий рассказ. Сегодня, например, сегодня мы ходили куда-то туда-то, мы делали то-то и то-то, мы видели... И потом мы это вместе читаем. И таким образом я ему показываю, как можно выражаться, чтобы, чтобы его поняли. Потому что как мы, насколько мы поняли... Ему, слова запоминать ему не трудно, слова запоминает он быстро, и словарный запас у него растёт. Но ему трудно выражаться так, чтобы его понимали другие. Возможно потому, что аутистам же трудно представить себя на месте других. И то, что он говорит - ему-то понятно? А для постороннего - это просто поток слов. И вот мы стараемся ему показать - как надо. Строить предложения, и как надо говорить связно, чтобы другие его понимали. И таким образом мы с ним занимаемся сейчас
Anna: Поняла вас.
kid still. He doesn't know how to do it yet. I mean, the main difficulty for him is to express himself in a way that he can be understood. To speak coherently. To construct sentences intelligently. To talk about something coherently. That is, when he begins to speak about something - it is received very often, some fragmentary short phrases. So you have to understand what he wants to say very often. In order to understand him. And that's what we're learning right now. For example, we... At one time we did a lot of work with pictures. He really likes to be photographed. What he's doing, familiar objects. For example, when we are on a walk, we often take pictures: of him and what he is doing and what we see, toys too. For example, he sits and plays, and he asks me to take a picture of him when he is playing. And afterwards he looks at those pictures. And we use that to talk about that topic of what happened, what he was doing. What he saw. And we also have a journal. We write together. When we go somewhere together, for example. He himself reminds us to write in our notebooks. I write what we did. So it turns out, as if a short story. Today, for example, today we went somewhere and there, we did this and that, we saw... And then we read that together. And that's how I show him how he can express himself, so that he can be understood. Because as far as we, as far as we understand... It's not hard for him to memorize words; he memorizes them quickly and his vocabulary grows. But it's hard for him to express himself in a way that others can understand. Perhaps because it is difficult for autistic people to imagine themselves in other people's shoes. And what he says is understandable to him, right? But to an outsider, it's just a flow of words. And so we try to show him how to do it. To form sentences, and how to speak coherently, so that others can understand him. And that's the way we're working with him now.

Anna: I understand.
7. Из того, что вы сказали мне показалось, что основные сложности - это именно в разговорной речи. В том, чтобы его понимали. Если бы вы оценили сейчас его развитие по шкале от 0 до 5 , где ноль - это вообще не нуждаются в помощи, а пять - это нуждается в очень значительной помощи. Где бы вы сейчас поставили?
Sofia: Hy, это трудно сказать. Это зависит от того, какая это ситуация. Потому что если это знакомая ему ситуация, например, если он дома и чего-то хочет - то он отлично может объяснить, что ему нужно. Если он сам не может взять. Например - взять принести что-то сам. Это он может. Или объяснить то, что ему нужно в данный момент. Ему труднее, когда эта ситуация незнакомая. Или, когда нужно говорить о чем-то абстрактным. О чем-то, что нельзя показать конкретно. Или, когда люди незнакомые. То есть с незнакомыми людьми, в незнакомой ситуации ему трудно объясниться. Когда. Когда. Действительно, когда ситуация такова, что нужно действительно, что связанная речь необходима для того, чтобы объяснить, что ему нужно. Потому что его проблема - именно в связной речи. Когда можно объяснить короткими фразами и показать, тогда он отлично объясняется. Сложность возникает когда нужно, например, какие-то абстрактные явления, чувства например. Он может сказать, что он устал, например, или както скучно, соскучился или что-то такое. Но когда более сложно - ему трудно объяснить. И также. Трудно понять, трудно узнать, например, что он понимает. Если ему что-то рассказали. То трудно, ему трудно объяснить, что он понял. Или он может, например, сидеть и смотреть какой-то фильм, но он не может объяснить, что он понял из него. Наверное, что-то понимает, раз он смотрит, раз ему интересно. Но вот что он понял и что он вынес из себя - это ему трудно объяснить. Ну и конечно же в школе это трудность, потому что в школе же... Очень часто нужно уметь. Объяснить. Что он понял из объяснений учителя, или из какого-то материала, и
7. From what you have said, it seemed to me that the main difficulties are precisely in speaking. It's about being understood. So, if you could characterize your child's development, including language development, on a scale of 0 to 5 , where 0 is "requires no extra help or support at all" and 5 is "requires a lot of support", where would you put him?

Sofia: Well, it's hard to tell. It depends on what kind of situation it is. Because if it's a situation he's familiar with, for example, if he's at home and wants something, then he can explain perfectly well what he needs. If he cannot take it himself. For example, to take something by himself. He can do that. Or he can explain what he needs at the given moment. It is more difficult for him when this situation is unfamiliar. Or when he has to talk about something abstract. Something that can't be shown concretely. Or when people are unfamiliar. That is, with unfamiliar people, in unfamiliar situations, it's hard for him to explain himself. When. When. Really, when the situation is such that one needs really, that connected speech is necessary in order to explain what he needs. Because his problem is precisely with connected speech. When you can explain in short phrases and show, then he explains perfectly. The difficulty arises when he needs, for example, some abstract phenomena, feelings for example. He can say that he is tired, for example, or somehow bored, bored or something like that. But when it is more complicated, he finds it difficult to explain. And also. It's hard to understand, it's hard to know, for example, what he understands. If he is told something. Then it's hard, it's hard for him to explain what he understood. Or he can, for example, sit and watch some movie, but he can't explain what he understood from it. He probably understands something, since he is watching it, since he is interested. But what he understood and what he got out of it is hard for him to explain. And, of course, at school it's difficult, because at school. Very often you have to be able to. Explain. What he understood from the explanation of the teacher, or from some material, and it is difficult for him. And also, for example, reading... I have tried reading stories with him, and he only wants to read about

ему это трудно. И к тому же, например, чтение... Я с ним пробовала читать рассказы, а он хочет читать только о себе. Ему не интересно читать ни о чем, кроме себя. Вот я ему пишу этот дневник - вот это он и читает. Потом, есть у него какие-то любимые...
Anna: Книжки?
Sofia: Ну да. Одно время у Чуковского очень любил, и до сих пор он Айболита вспоминает. Мы с ним вместе рассказываем: я читаю, и он дополняет, вставляет слова.
Anna: Что-то рифмующееся ему нравится?
Sofia: Да, ну иногда... То, есть, например Айболита этого. Я ему читаю, мы, например, на прогулке, иногда он сам начинает рассказывать. Я говорю предложение - он дополняет. Иногда специально что-то вставляет не то. Например, там, где доктор Айболит "И всем по порядку даёт..." Он говорит: «Вертолёт». Нет. «Всем по порядку даёт...»《». Просто в шутку начинает что-то вставлять.
Anna: Понятно.
Sofia: Так вот, трудно его заинтересовать чем-то, что не входит в его сферу интересов.
Anna: Понятно. Возвращаясь к языкам дома.

## 8. Похоже, что родными языками у вас являются в семье русский, шведский и испанский. И вы упомянули, что используется шведский язык только когда, принимаете гостей в анкете.

Sofia: Да. Но у нас как получается... Если у нас, если пришёл человек, который не знает русского и испанского. То мы с ним говорим по-шведски. Но с детьми все равно на русском и испанском. У нас как повелось с самого начала, как дочка родилась. Так с самого начала и было. То я с ней говорю только по-русски, она со мной только порусски. С папой только по-испански, между собой по-испански. То есть шведский у нас всегда был в детском саду, в школе. Ну за исключением тех случаев, когда кто-то приходит. Тогда с этим человеком мы говорим на понятном ему языке.
himself. He's not interested in reading about anything but himself. So I write him this diary, that's what he reads. Then, he has some favorites...

Anna: Books?
Sofia: Well, yes. At one time he was very fond of Chukovsky, and he still remembers "Aibolit". We tell stories together: I read, and he completes it, inserts words.

Anna: He likes something that rhymes?
Sofia: Yes, well, sometimes... I mean, for example, Aibolit. I read to him, for example, we're on a walk, sometimes he starts to tell the story himself. I say a sentence, he completes it. Sometimes he puts something in on purpose that is not right. For example, where Dr. Aibolit says, "And he gives to all in order..." He says, "Helicopter." No. "He gives everybody..." "A streetcar." He just starts inserting something in as a joke.

Anna: I see.
Sofia: So, it's hard to get him interested in something that's not in his area of interest.

Anna: I see. Going back to the languages at home.
8. It looks like your native languages are Russian, Swedish, and Spanish. And in the survey you mentioned that you only use Swedish when you receive guests.

Sofia: Yes. But the way it works for us... If we have, if a person visits who doesn't know Russian or Spanish. Then we speak to him in Swedish. But we still speak Russian and Spanish with the kids. It has been our tradition from the very beginning, when our daughter was born. So from the very beginning it was. I speak to her only in Russian, she speaks to me only in Russian. With dad - only in Spanish, between each other in Spanish. So we always had Swedish in kindergarten, at school. Well, except when someone comes. Then we speak to that person in a language he or she understands.
9. А вне дома тоже получается, что в основном шведский, испанский, русский языки он слышит. Не могли бы вы рассказать: где и как часто?
Sofia: B школе на шведском конечно. Вне дома. Так у нас родственники есть испаноязычные. Бабушка иногда приезжает из Таллина. Бабушка порусски.
10. А сами вы ездите домой? В Эстонию или в Перу.
Sofia: Да, иногда ездим. Правда, до этой пандемии конечно было чаще. До пандемии дочка обычно ездила к бабушке на каникулы в Таллин. Ещё троюродные брат и сестра тоже вместе ездили. К бабушке. И один раз ездила с папой к другим бабушке и дедушке в Перу. И мы часто делали так? Что мы и едем все вместе в Таллин. На пароме. Потом дочку оставляем там, у бабушки. А сами едем обратно. С (имя). Для него это тоже поездка на пароме. Для него это событие. Но это давно было, ещё до пандемии. Пару лет вообще никто из родственников не мог приехать. В этом году бабушка смогла. Или в прошлом году бабушка смогла выбраться к нам.
11. Во время пандемии, наверное, только по скайпу или по зуму общались с бабушкой той же?
Sofia: Интернет телефон. Так... Трудно было с родственниками. Ну, за исключением тех испаноязычных родственников, которые здесь живут. Но с ними то же там. То один коронавирусом заболел, то там собирались... Когда дочке 10 лет исполнилось. Конечно, большой праздник не устроить. Подумали, может быть, хоть родственники приедут. А в это время они коронавирусом заболели.
Anna: Понятно.
12. Вы ещё отметили, что читаете ему книжки только на русском языке, но при этом смотрите телевизор, нетфликс, какие-то другие действия на шведском и на русском. Почему именно книжки на русском?
Sofia: Он сам выбирает что смотреть. Смотрит на разных языках. Я детям всегда читаю на своём родном языке.
13. Папа читает книжки?
9. And outside the home, too, it turns out that he hears mostly Swedish, Spanish, and Russian. Could you tell more: where and how often?
Sofia: At school in Swedish, of course. Outside the home. So we have Spanishspeaking relatives. The grandmother sometimes comes from Tallinn. Grandma speaks Russian.
10. Do you travel home yourself? To Estonia or Peru.
Sofia: Yes, sometimes we do. Before the pandemic, of course, it was more often. Before the pandemic, my daughter used to go to her grandmother in Tallinn for vacations. Her third cousins also went together. To her grandmother's. And once she went with her dad to visit the other grandparents in Peru. And we did that a lot? That and we go all together to Tallinn. On the ferry. Then we leave our daughter there with her grandmother. And we travel back ourselves. With (name). For him it's also a ferry trip. For him it's an event. But that was a long time ago, even before the pandemic. For a couple of years none of the relatives could come at all. This year - grandma was able to. Or last year - grandma was able to come out to see us.
11. During the pandemic, did you probably only use Skype or zoom to talk to his grandmother?
Sofia: Internet phone. So... It's been hard with relatives. Well, except for those Spanish-speaking relatives who live here. But with them there too. One of them got coronavirus, one of them was going to... When my daughter turned 10 . Of course, we couldn't have a big party. We thought that maybe at least the relatives would come. And at that time they got Coronavirus.

Anna: I see.
12. You also noted that you only read books to him in Russian, but you watch TV, Netflix, do some other activities in Swedish and in Russian. Why only books in Russian?

Sofia: He chooses what to watch. He watches in different languages. I always read to my children in my native language. 13. Does his dad read books?

Sofia: Папа - да. Но у них получается так, его немножко трудно заинтересовать. Но папа с ним смотрит, у него есть книжки, например, о животных. Любимые книжки. Папа с ним вместе рассматривает картинки, и они говорят о том, что там. То есть там, можно сказать - это факты познавательные о животных. С папой это смотрит. Потом фильмы они смотрят. Он сейчас Гарри Поттера любит смотреть. На испанском.
Anna: Понятно.
14. И вы ещё полностью согласны с утверждением, что билингвизм важен для вашего аутичного реб̈̈нка, и также для вашей дочки, которая нейротипичный ребёнок. Не могли бы вы подробнее рассказать об этих решений, как вам кажется, почему он важен?
Sofia: Ну, это уже такая тема, я думаю что даже не для магистерской работы для десяти докторских диссертаций.
Anna: Да.
Sofia: Помимо тех сотен диссертаций, которые уже написаны на эти темы.
Anna: Наверное (смех). Но конкретно для вас. Мы не берём учёных, которые этим занимаются (смех).
15. Для вас вообще, что такое билингвизм. Какое определение вы бы дали?
Sofia: Да но для меня... Учитывая, что я сама лингвист.
Anna: Понятно.
Sofia: И то, что я сама изучаю языки всю жизнь...
Anna: Но все таки поподробнее для вас, что это? Равное знание языков или просто владение несколькими языками?
Sofia: Ну как сказать, чёткого определения ведь нету. Ни чёткого определения нельзя дать, ну потом - что значит в равной степени? Потому что, язык же не измеряется по шкале от нуля до 100 . Это скорее. Ну вот. Потому что владение языком - ведь нельзя измерять просто по шкале от нуля до ста или до сколько-то там или какого-то там совершенства, о котором любят говорить. Знать язык в совершенстве. Я понятия не имею. С образованием ни одного языка в совершенстве не знаю. И даже не понимаю, что это такое.

Sofia: Dad, yes. But they have it so, it's a little difficult to get him interested. But dad watches with him, he has books, for example, about animals. Favorite books. Dad looks at the pictures together with him, and they talk about what's in there. That is there, you could say - these are educational facts about animals. With dad - watching it. Then they watch movies. He likes to watch Harry Potter now. In Spanish.

Anna: I see.
14. And you also completely agreed with the statement that bilingualism is important for your autistic child, and also for your daughter, who is a neurotypical child. Could you elaborate on those decisions as to why you think it's important?

Sofia: Well, this is such a topic, I think, not even for a master's thesis - for ten doctoral dissertations.
Anna: Yes.
Sofia: In addition to the hundreds of dissertations already written on these topics. Anna: Probably (laughing). But specifically for you. We won't consider scientists who study it (laughing).
15. For you in general, what is bilingualism? What definition would you give?
Sofia: Yes, but for me... Considering that I'm a linguist myself.
Anna: I see.
Sofia: And the fact that I myself have been learning languages all my life...
Anna: But more specifically for you, what is it? Equal knowledge of languages, or just the ability to speak several languages?
Sofia: Well, there's no clear definition. You can't give a clear definition, and then what does it mean - equally? Because language is not measured on a scale from zero to 100 . It's more like. There you go. Because language proficiency, you can't just measure it on a scale of zero to a hundred or whatever or whatever perfection they like to talk about. To know a language perfectly. I have no idea. With my education, I don't know any language perfectly. And I don't even understand what it is.

Anna: Конечно.
Sofia: Но язык, это ведь, можно сказать, это скорее как дерево. То есть идёт ствол, ветки. Большие ветки разлетаются на маленькие, то есть это целый комплекс разных, разных навыков: и разговорная речь, и чтение, и письмо, и словарный запас в самыхсамых разных. Из разных областей. И иногда даже трудно сказать какое дерево выше. Например, дерево, одно дерево может быть высокое, но тонкое, а другое может быть толстое и ветвистое. А у третьего может быть ствол тоненький, зато очень много-много-много разных веток. И вот какое из этих деревьев больше? Вот так и с языками. Может быть он, ребёнок может знать что-то. Что-то, например, чем-то может владеть на шведском, то, чему в школе учили. Но в то же время. В какой-то другой ситуации может перевесить словарный запас на другом языке. То есть вот так сравнивать-то очень сложно.
Anna: Понимаю вас. Очень красивая метафора. Спасибо.
Sofia: К сожалению многие этого не понимают. Начинают измерять в процентах. Ну как можно измерить, как можно измерить знание языка в процентах? Вот сколько процентов космоса мы можем увидеть. Я на родном языке, например не все знаю.
Anna: Конечно. Такой ещё вопрос.
16. В вопросе $\quad$ возможных препятствиях, которые могли бы вас беспокоить в связи с билингвизмом вашего аутичного ребёнка вы ничего не выбрали. Как бы вы это обосновали? Не видите препятствий? Sofia: Ну в каком смысле препятствий. У него сложности с речью, но они у него есть на всех языках. И мы, кстати, не так давно консультировались как раз с логопедами. Нам в школе посоветовали обратиться к логопедам, потому что до этого, когда он был совсем маленький, он не захотел. Он вообще не хотел участвовать ни в каких тестах. Вообще он терпеть не может всякие тесты. Ненавидит, когда его тестируют, задают вопросы.
Anna: Его можно понять.
Sofia: Да. И когда мы проходили обследование и когда ему ставили

Anna: Of course.
Sofia: But language, you could say it's more like a tree. That is, there is a trunk, branches. The big branches break up into smaller branches, so it's a whole complex of different, different skills: speaking, reading, writing, and vocabulary in the very different areas. From all sorts of different areas. And sometimes it's even hard to tell which tree is higher. For example, a tree, one tree might be tall but thin, and another might be thick and branchy. And the third may have a thin trunk, but many, many different branches. And which of these trees is bigger? It's like that with languages. Maybe he, the child may know something. Something, for example, something he might know in Swedish, something he learned in school. But at the same time. In some other situation, it may outweigh the vocabulary in another language. So it's very difficult to compare like that.

Anna: I see your point. It's a very beautiful metaphor. Thank you.
Sofia: Unfortunately, many people don't understand this. They start to measure it in percentages. Well, how can you measure, how can you measure language skills as a percentage? That's how much of the space we can see. I don't know everything in my native language, for example.
Anna: Of course. There's another question.
16. In the question about possible obstacles that might concern you about your autistic child's bilingualism, you didn't choose anything. How would you explain this? You don't see any obstacles?

Sofia: Well, what do you mean obstacles. He has difficulties with speech, but he has them in all languages. And we, by the way, consulted speech therapists not too long ago. We were advised by the school to go to speech therapists, because before, when he was very young, he didn't want to. He didn't want to participate in any tests at all. In general he hates all kinds of tests. He hates being tested, he hates being asked questions.

Anna: It's understandable.
Sofia: Yes. And when we were being examined and when he was being

диагноз, то в кабинете логопеда он заснул. Просто сел и заснул сидя.

Anna: Увлекательное такое
тестирование было? (смех)
Sofia: Но в этот раз мы решили тогда... Мы с ним вместе ходили в логопедическое отделение, и там я сказала, что мы используем русский и испанский. И нам тогда назначили две встречи. С логопедом, который немного говорит по-русски и плюс с русским переводчиком. По телефону. И две встречи с испаноязычным логопедом. Но там правда получилось так, что у него... У (имя) у него на любую непонятную ситуацию у него реакция гиперактивность. То есть он может спокойно сидеть дома, когда он оказывается в новом месте среди незнакомых людей и не знает, что ему делать, то он начинает бегать, везде забираться, озорничать, шуметь. И в общем было очень трудно. Заставить его как-то сосредоточиться. Но с русскоговорящим логопедом ещё хоть как-то мы. Немного с ним поговорить. У неё были картинки какие-то. Потом нам удалось. Удалось нам заниматься в комнате, где можно было бегать и кувыркаться. Там была доска, где он мог что-то там написать. Он там сразу стал на доске писать. И в общем, как-то хоть что-то он там сказал, по картинкам. И переводчик послушал, там что-то они могли оценить, как он падежи употребляет, как он говорит. В общем что-то он там сказал, что-то смог сказать. Хотя и не очень много очень. Много отвлекался и бегал. Потом, когда пришёл на две другие встречи. Когда был логопед испаноязычный. Там он не захотел. Потому что он в присутствии меня он привык говорить по-русски. А логопед для него незнакомый человек, ему было не очень интересно, и он начал бегать и вызывать лифт, бегать по коридору, кричать, пугать рыбок в аквариуме, пугать пациентов. И мы попробовали тогда, чтобы я отошла, и чтобы он зашёл в кабинет с логопедом и побыл только с ней. Она говорила, что он там ей стал только по-русски отвечать. В результате нам пришлось тогда вместо этой встречи.
diagnosed, he fell asleep in the speech therapy office. He just sat down and fell asleep sitting up.
Anna: Must have been a fascinating test? (laughing)
Sofia: But this time we decided then... He and I went to the speech therapy department together, and there I said that we would use Russian and Spanish. And we had two appointments then. With a speech therapist who spoke a little bit of Russian and plus with a Russian interpreter. On the phone. And two meetings with a Spanish-speaking speech therapist. But it really turned out that he had... (name) has a reaction to any incomprehensible situation - hyperactivity. That is, he can sit quietly at home, but when he finds himself in a new place among strangers and doesn't know what to do, he starts running around, getting everywhere, making naughty noises. And in general it was very difficult. Getting him to focus somehow. But with a Russian-speaking speech therapist we were able to do something. To talk to him a little bit. She had some pictures. Then we managed. We managed to study in a room where we could run and tumble around. There was a board where he could write something there. He started writing on the board right away. And anyway, somehow he said something there, from the pictures. And the interpreter listened, there was something they could assess, how he used cases, how he spoke. So he said something, he was able to say something. Although not very much. He was distracted and running around a lot. Then when he came to the other two meetings. When there was a Spanish-speaking speech therapist. There he didn't want to. Because he was used to speaking Russian in my presence. And the speech therapist was a stranger to him, he wasn't very interested, and he started running and calling for the elevator, running down the hall, screaming, scaring the fish in the aquarium, scaring the patients. And we tried then to get me to step back and have him go into the office with the speech therapist and just be with her. She said that he only responded to her in Russian. As a result, we had to have that meeting instead. Scheduled. To make the meeting online only with his dad. Then he was in the presence of his dad, he and dad

Запланированной. Сделать встречу онлайн только с папой. Тогда он в присутствии папы, они вместе с папой общались, и тогда была встреча по видео, по зуму.
Anna: С испанским логопедом, да?
Sofia: C испаноязычным логопедом. Тогда логопед мог понаблюдать как он играет и общается с папой. И тогда уже дома, в знакомой обстановке. И тогда она уже могла это услышать.

Anna: То есть они фактически тестировали оба его домашних языка?
Sofia: Да. И потом пришли к выводу, что, как и я говорю, что у него сложность не в самом языке, а в том, что у него из-за аутизма ему трудно представить себе, как надо говорить, чтобы его понимали. Так что в общем пришли к выводу, что как мы с ним работаем, пожалуй, это для него и есть. Наилучший выход.
Anna: A забегая немножко наперёд. Вопрос про специалистов.
17. Как вам кажется вообще: вы получаете достаточную помощь или хотели бы какую-то ещё помощь получать от государства, от школ, от врачей?
Sofia: Он ходит сейчас в спец-класс. Он ходит в (название школы), В маленький класс. Где с ним специально занимаются. Специальные педагоги. Иии. Он ездит на такси. В 7 утра за ним приезжает такси, он едет в школу. И там он на продлёнке остаётся до пяти. Так что я думаю, что к школе, в школе он получает поддержку. И там ему нравится. В общем-то.
18. И в школе на каких языках они говорят?
Sofia: Школа-то. Шведская, но...
Anna: Ну мало ли там, ассистенты, допустим на других языках...
Sofia: Там кто-то есть, там есть ещё у них работник русскоговорящий. Кто-то среди работников. Но они знают, что мы общаемся и дома на русском и испанском.
19. Как вам кажется, они поддерживают его билингвизм. Предоставляя материал на других языках или?
communicated together, and then there was a meeting by video, by zoom.

Anna: With a Spanish speech therapist, right?
Sofia: With a Spanish-speaking speech therapist. Then the speech therapist could watch him play and communicate with his dad. And then at home, in a familiar environment. And then she could hear it already.
Anna: So they were actually testing both of his home languages?
Sofia: Yes. And then we came to the conclusion that, as I say, his difficulty is not in the language itself, but in the fact that, because of his autism, he has difficulty imagining how to speak in order to be understood. So all in all we came to the conclusion that the way we work with him is probably the way it is for him. The best way out.
Anna: And getting a little ahead of ourselves. A question about specialists.
17. What do you think in general: do you get enough help or would you like to get some more help from the state, from schools, from doctors?

Sofia: He goes to a special class now. He goes to (name of the school), a small class. Where he has special classes. Special teachers. Aaand. He takes a cab. At 7:00 in the morning, a cab picks him up, he goes to school. And there he stays in after-school care until five. So I think by school, at school, he gets support. And he likes it there. Basically.

## 18. And what languages do they speak at school?

Sofia: The school. Swedish, but...
Anna: Well, let's say, maybe there are some assistants, in other languages...
Sofia: There's someone there, they also have a Russian-speaking employee. Someone among the employees. But they know that we also communicate at home in Russian and Spanish.
19. Do you think they support his bilingualism? By providing material in other languages or?

Sofia: Предоставить материал, я думаю, что все-таки легче нам. Потому что мы же знаем, что ему интересно. Я сама знаю, что ему интересно. И потом у меня ещё и старший ребёнок. И... Да. И по работе тоже, кстати, приходится. Я преподаю русский как родной язык. Так что у меня для учеников материалы есть.
20. Кстати, интересно, а вы какой будете выбирать предмет как родной язык в шведской школе ему: испанский или русский?
Sofia: Ну, пока что мы... Пока что мы ещё это не обсуждали в школе. Но это нужно будет обсудить. Конечно, в идеале. Я считаю, что если два разных языка дома, то надо было бы предоставить оба. Но, к сожалению, правила у нас не такие.
Anna: A испанский как второй иностранный? Не думали взять? Потому что у меня дочка, например испанский учит как второй иностранный.
Sofia: Дочка, например, она ходит на испанский как родной. Она ходит на испанский как родной. И на русском я стараюсь чтобы она читала регулярно, я ей говорю: «Хотя бы немножко. Хотя бы страничку, пару страничек». Чтобы регулярно читала. Потом я стараюсь ей читать вслух то, что посложнее. Ну вот. То есть можно сказать, что русским мы занимаемся дома, хотя редко пишем. Вот это не всегда успеваем. Я стараюсь, чтобы она читала. Но пишет она реже на русском. Иногда прошу, чтобы она чтонибудь написала. Морально готовлюсь к худшему. Смотрю - ну вроде как ошибок не так уж и много.
Anna: Не все так плохо (смех).
Sofia: Не так уж и плохо. Потому что я смотрю, чтобы она читала. Потому что чтение ведь очень важно. А с (Имя) мы ещё... Не знаю.
Anna: Не обсуждали?
Sofia: В любом случае мы поддерживаем оба дома. И то, что делается дома, ведь на самом деле это даёт намного больше, чем час в неделю. В школе - это же все равно, больше часа в неделю никак не получится. Ещё по ученикам тоже очень ясно видно. Я считаю. Кто дома занимается, а кто нет. Потому что для тех, у кого дома много шведского. Они могут прийти и после

Sofia: To provide material, I think it's still easier for us. Because we know what he's interested in. I myself know what he's interested in. And then I also have an older child. And... Yeah. And it's my job, too, by the way. I teach Russian as a mother tongue. So I have materials for my students.
20. By the way, I wonder which subject you will choose as his mother tongue at Swedish school for him: Spanish or Russian?
Sofia: Well, so far we... Haven't discussed it at school. But it will have to be discussed. Of course, ideally. I think that if there are two different languages at home, we should be provided with both. But, unfortunately, that's not how it works in our rules.

Anna: And Spanish as a second foreign language? Have you thought about taking it? Because my daughter, for example, learns Spanish as a second foreign language here.
Sofia: My daughter, for example, she takes Spanish as her mother tongue. She takes Spanish as her mother tongue. And in Russian I try to get her to read regularly, I tell her, "At least a little bit. At least a page, a couple of pages." So she reads regularly. Then I try to read aloud to her what's more difficult. Here we go. So, we can say that we study Russian at home, although we rarely write. We don't always manage to do that. I try to get her to read. But she writes less often in Russian. Sometimes I ask her to write something. Mentally I prepare myself for the worst. I look, well, it seems like there aren't too many mistakes.

Anna: It's not that bad (laughing).
Sofia: It's not that bad. Because I make sure that she reads. Because reading is very important. And with (Name) we're still... I don't know.
Anna: Haven't discussed it?
Sofia: Anyway, we support both at home. And what's done at home, because it actually gives a lot more than an hour a week. At school, it's still, there's no way you can get more than an hour a week. It's also very clear looking at the students, too. I think. Who's studying at home and who's not. Because for those who have a lot of Swedish at home. They can come and forget everything after the vacations. After the vacations, they can

каникул все забыть. После каникул могут начисто забыть все, что проходили. А вот. Особенно те, кто дома не говорят регулярно, а те у кого дома много шведского. Им труднее всего. Потому что те, у кого дома регулярно говорят и регулярно используют язык, читают. Конечно, это совсем другая. Совсем другой уровень. Таких очень. Вот и мы дома стараемся поддерживать оба. То есть у обоих детей: и дочь, и сын. Конечно, их возможностей, в силу их знаний.
Anna: Понятно.
Sofia: С дочкой по-другому, конечно.
Anna: Я вас понимаю, да.
21. А в чем вы видите вооб́ще относительные преимущества жизни в двуязычной домашней среде для детей в смешанных браках?
Sofia: Ну как. Преимуществ очень много. Хотя бы то, что знаний. Знание языка - это уже плюс. Знание языков, знакомство с разными культурами, возможность общаться с родственниками в другой стране. Или, как в нашем случае. Дети могут общаться с родственниками и из Эстонии, и из России, и из Перу. Так что. Потом. Сам по себе. Само по себе двуязычие развитие. Способствует когнитивный навыкам. Так что плюсов очень много.
Anna: Хорошо. То есть минусов вы не видите?
Sofia: Ну, какие могут быть минусы в знаниях? Знания никак не могут быть минусом. Другое дело, что не всегда удаётся. Например заниматься. То есть для того, чтобы почитать книжки на разных языках нужно больше времени. То есть чтение на разных языках занимает больше времени, чем чтение на одном языке. Но это же не минус.
Anna: Да. Нехватка времени просто.
Sofia: Просто это просто нехватка времени. В любой сфере такое будет. Если заниматься двумя видами спорта, то меньше времени будет. Играть на двух музыкальных инструментах. Например, займёт больше времени, чем игра только на одном. Но это же не значит, что, например, играть на
forget everything they've learned. And here. Especially those who don't speak regularly at home, and those who have a lot of Swedish at home. They have the hardest time. Because those who speak regularly at home and use the language regularly - they read. Of course, it's a very different thing. A very different level. There are a lot of those. So we try to support both (languages) at home. I mean, both children have it: both daughter and son. Of course, their capabilities, by virtue of their knowledge.

Anna: I see.
Sofia: It's different with my daughter, of course.
Anna: I understand you, yes.
21. What do you see as the relative advantages of living in a bilingual home environment for children in mixed marriages in general?
Sofia: Well, how. There are a lot of advantages. At least the knowledge. Knowing the language is already a plus. Knowing languages, getting to know different cultures, the opportunity to communicate with relatives in another country. Or, as in our case. Children can communicate with relatives from Estonia, Russia, and Peru. So. Then. By itself. Bilingualism itself is. Promotes cognitive skills. So there's a lot of pluses.

Anna: Okay. So you don't see any minuses?
Sofia: Well, what disadvantages could there be in knowledge? There is no way knowledge can be a disadvantage. Another thing is that you don't always succeed. For example to study. That is, it takes more time to read books in different languages. That is, reading in different languages takes more time than reading in one language. But this is not a minus.
Anna: Yes. There's just not enough time.
Sofia: It's just a lack of time. It will happen in any field. If you play two sports, there will be less time. Playing two musical instruments. For example, it will take more time than playing only one. But that doesn't mean that playing violin and saxophone, for example, is worse than playing only violin.

скрипке и на саксофоне хуже, чем играть только на скрипке.
Anna: Да, я с вами согласна. Некоторые правда используют логику, что лучше на одном научиться, чем плохо на двух.

Sofia: Плохо только, плохо на одном. Разве есть научные доказательства. Потому что это помогает.
Sofia: Мы уже выяснили, у нас сложности не в языках, а в том что ему трудно выразить свои мысли на любом языке. И ещё такой небольшой момент. У нас дома. Когда он только начинал говорить, когда он вообще мало говорил. Он в садике говорил очень мало. Дома он что-то мог выразить лучше на русском, что-то на испанском. Вот допустим, отказываться от какогото языка. От какого? (с сарказмом) Неужели от шведского? Он на нем все равно мало говорит. Но ему все, все языки ему помогают. То, что он не может сказать на одном, он, может быть, сможет рассказать. То, что он не может объяснить мне, например. То он, может быть, сможет объяснить папе поиспански и наоборот. Это его языковой капитал. И слова он запоминает быстро. Он может один два раза услышать слова и запомнить. Так что у него трудность не в этом. А трудность у него, когда начинается. Словарный запас у него растёт. У него трудности начинаются главным образом в синтаксисе. То есть строить предложения. И рассказывать связано. Но это он, это ему на любом языке трудно.
22. Да. То есть из того, что вы рассказали я вижу, что вы в семье используете политику "Один родитель-один язык"? То, что вы говорите на русском...
Sofia: Да, так можно сказать. Хотя дети прекрасно знают, что я говорю и поиспански, и по-шведски. Но он со мной, все равно со мной - это русский. Как с самого начала было, так и есть.
23. Как вы вообще изначально, вы сами решили так поступить в семье? Или вам кто-то посоветовал?
Sofia: Ну как. Это как-то получилось, как нечто само собой разумеющееся. Уже даже не обсуждалось.

Anna: Yes, I agree with you. Some people just use the logic that it's better to learn to play one instrument than to play poorly on two.
Sofia: It's only bad, bad on one thing. Is there any scientific evidence. Because it helps.
Sofia: We've already figured out that it's not the languages we're having trouble with, it's that he's having trouble expressing himself in any language. And then there's this little thing. At our house. When he first started speaking, when he didn't speak much at all. He spoke very little in kindergarten. At home, he could express something better in Russian and something in Spanish. Let's say, giving up a language. Which one? (with sarcasm) Swedish maybe? He doesn't speak it much anyway. But everything, all languages help him. What he cannot say in one, he may be able to say. What he can't explain to me, for example. Maybe he can explain to dad in Spanish, and vice versa. That's his language capital. And he remembers words fast. He can hear the words once or twice and remember them. So that's not the difficulty he has. That's not his problem, it's when he starts. His vocabulary is growing. His difficulty starts mostly in syntax. That is, building sentences. And telling connected stories. But that's him, that's difficult for him in any language.
22. Yes. So, from what you have told me, I see that you use the "one parent, one language" policy in your family? The fact that you speak Russian...

Sofia: Yes, you could say that. Although the children know very well that I speak both Spanish and Swedish. But it's with me, it's still with me - it's Russian. As it has been from the beginning, it is.
23. How did you initially decide to do this in your family? Or did someone advise you to do it?
Sofia: Well, how. It somehow turned out to be something that I took for granted. It wasn't even up for discussion anymore.

Anna: Для вас это было настолько естественным, что...
Sofia: Да. Для меня было естественно, что говорить с детьми на том же языке, на котором со мной в детстве говорила моя мама.
24. А вот родственники разделяли ваше мнение?
Sofia: Ну, родственники спрашивали: «На каком языке будете говорить?» Но вот, каждый на своём.
25. И как они в целом относятся к языковой ситуации?

Sofia: Бывает, что хвалят. Говорят: «Молодцы, дети». Но потом мои родственники, я думаю, уже ничему не удивляются.
Anna: То есть они одинаково относятся
к билингвизму что нейротипичного ребёнка, что и ребёнка с диагнозом?
Sofia: Ну да.
Anna: Хорошо.
26. И вы ещё ответили, что не используете дома каких-то вспомогательных систем помощи или визуального расписания. Вы когданибудь пользовались им или рассматривали возможность начать пользоваться?
Sofia: Ну как сказать... Визуальное расписание у нас. У них в школе используется, у (имя). Дома просто както не было необходимости, потому что ему и так все понятно. С дочкой нормотипичной использовали как-то вот такую схему, когда нужно было несколько лет назад. Когда она собиралась в школу. Потому что она могла вот так сесть и забыть, что ей надо собираться. Так что вот тогда у меня было расписание для неё. О том что нужно, что нужно успеть сделать утром: позавтракать, одеться, почистить зубы, идти... А-то она могла сесть, забыть и начать делать что-то не то.
Anna: На каком языке оно было?
Sofia: И песочные часы тоже были.
27. А в школе эти все визуальные вспомогательные расписания они на шведском, наверное, или вообще без языка?
Sofia: Там у него на шведском. А так, дома? Мы только в некоторых ситуациях, когда казалось, что ему

Anna: It was so natural for you that...
Sofia: Yes. It was natural for me to speak to my children in the same language that my mother spoke to me as a child.

## 24. Did your relatives share your opinion?

Sofia: Well, the relatives asked, "What language will you speak?" But there you go, each - in his own language.
25. And how do they generally relate to the linguistic situation?

Sofia: Sometimes they praise me. They say, "Well done, kids". But then my relatives, I think, are no longer surprised.

Anna: So they treat the bilingualism of a neurotypical child the same as that of a child with a diagnosis?
Sofia: Yeah.
Anna: Good.
26. And you also answered that you don't use any augmentative systems or visual scheduling at home. Have you ever used one or considered starting?

Sofia: Well, how can I put it... We have a visual schedule. They use it at (name)'s school. At home we just didn't need it, because he understands everything anyway. With my normotypical daughter, we used this chart once, when we needed it a few years ago. When she was going to school. Because she could sit down and forget that she had to get ready. So that's when I had a schedule for her. About what she had to, what she had to do in the morning: get breakfast, get dressed, brush her teeth, go... Otherwise she could sit down, forget, and start doing something wrong.

Anna: What language was it in?
Sofia: We also had an hourglass.
27. And at school, are all these visual schedules in Swedish, I guess, or no language at all?

Sofia: It's in Swedish. And so, at home? We - only in certain situations when it seemed difficult for him, to do what he needed to do.

трудно что нужно делать. В отдельных ситуациях мы это использовали. А так, ему в общем-то более или менее ясно, что нужно делать. Знакомые ситуации.
28. В вашей семье, как вам кажется, кто принимает основные решения о развитии, его языковом развитии в развитии в целом?
Sofia: Ну, в каком смысле решения?
Anna: Ну, вот допустим, не знаю, какой основной родной язык взять в школе. Кто основное решение будет принимать?
Sofia: Ну, дочку я записывала на испанский. А так? Как, советуемся, наверное? И потом тоже ещё. Что касается решений по поводу языков, лингвистическое образование у меня.
Anna: Вы берете на себя роль эксперта, в какой-то степени. Понятно.
28. Вот вы ещё в анкете отметили, что учительница вашего сына давала вам совет когда-то воспитывать его на двух языках сразу. То есть в целом вы видите поддержку или нет? Билингвизма в вашей семье от учителей, от других специалистов?
Sofia: Да, конечно. То есть, да, конечно. У нас... Учителя нас поддерживают. И к тому же. Мы живём в таком районе, где билингвами уже никого не удивишь. Вот у моей дочки, мы в (название района). У неё в классе, по-моему, все билингвы, трилингвы. Поэтому белой вороной почувствует себя ребёнок, который говорит только по-шведски.
29. И тоже там был вопрос о советах социальных сетей, интернет-форумов, незнакомцев, знакомых. Вы ответили, что не получаете никаких советов. Не могли бы вы рассказать поподробнее. Вы просто не рассматриваете советы из таких источников?
Sofia: Ну как. Я рассматриваю советы, если это советы профессионалов. Смотря, кто скажет, конечно же. То есть советы учителей и экспертов я, конечно, рассмотрю. Но они не идут. Советы, советы например логопедов, учителей не идут вразрез с тем, что... С моим собственным мнением.
Anna: Мы плавно подходим на самом деле к концу. Такой вопрос.

In certain situations we used that. And so, it's generally more or less clear to him what he needs to do. Familiar situations.
28. In your family, who do you think makes the major decisions about his development and language development in general?
Sofia: Well, what do you mean, decisions?
Anna: Well, let's say, I don't know, which primary mother tongue to take at school. Who's going to make the main decision?

Sofia: Well, I enrolled my daughter in Spanish. How about this? Like, we have a discussion, I guess? And then there's more, too. As far as language decisions, I have a linguistic background.
Anna: You take on the role of an expert, in a way. I see.
28. You also mentioned in your questionnaire that your son's teacher once advised you to raise him in two languages at once. So in general, do you see support or not? In terms of bilingualism in your family, from teachers, from other professionals?
Sofia: Yes, of course. I mean, yes, of course. We have... The teachers support us. And also. We live in a neighborhood where no one's surprised by bilinguals anymore. My daughter, we're in (name of district). In her class, I think, everyone is bilingual, trilingual. So a child who speaks only Swedish would feel like a black sheep.
29. And there, too, was a question about advice from social networks, Internet forums, strangers, and acquaintances. You answered that you don't get any advice. Could you tell me more about that. Do you not consider advice from such sources?
Sofia: Well. I'm considering advice if it's professional advice. Depends on who's giving it, of course. I mean, advice from teachers and experts I'll consider, of course. But they don't. Advice, advice from e.g. speech therapists, teachers don't go against what... With my own opinion.

Anna: We're really coming to an end. Such a question.
30. Какие у вас планы на будущее в отношении образования и развития вашего сына?
Sofia: Ну. Тут уже загадывать трудно. Я думаю, что мы будем действовать по тому, по его... Возможностям. Потому что у него есть определенные трудности, но трудно загадывать на будущее. Как у него пойдет. Пока что он только что в третьем классе. Так что мы будем уже смотреть по результатам, что ему понадобится. Что у него будет лучше получаться. Так что исходить из того, что... Из его результатов. Из его успехов. Anna: Будете смотреть по обстановке?
Sofia: Да, конечно же. По ситуации. По его результатам, его способностям, его желанием.
31. Последний вопрос: если чтонибудь, что бы вы хотели добавить, что как вам кажется мы не обсудили. Или спросить меня о чем-то?
Sofia: Я думаю, что тут, это такая тема, которую можно обсуждать. Тема, которую можно обсуждать часами.
Anna: Хорошо. Давайте я тогда остановлюсь сейчас запись и просто расскажу про мою работу. Просто пообщаемся сейчас.
30. What are your future plans for your son's education and development?

Sofia: Well. It's hard to know. I think that we'll act according to his... Possibilities. Because he has some challenges, but it's hard to know what the future holds. How he's going to do. So far, he's just in the third grade. So we'll just see from the results, what he's going to need. What he's going to be better at. So, to judge that from what... From his results. From his progress.

Anna: According to the situation?
Sofia: Yes, of course. According to the situation. According to his results, his abilities, his desire.
31. Last question: if there's anything you'd like to add that you don't think we've discussed. Or ask me something?

Sofia: I think here, this is the kind of topic that can be discussed. It's a topic that could be discussed for hours.
Anna: Okay. Let me stop the recording now and just talk about my project. Let's just talk now.

## Appendix M

Number of respondents (and \%) and their ratings of their autistic children' language skills

| Comprehension |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | more than ageappropriate | ageappropriate | less than ageappropriate | much less than ageappropriate | not at all | total <br> (n) |
| Language 1 | 9 (22.50\%) | 11 (27.50\%) | 15 (37.50\%) | 5 (12.50\%) | 0 (0.00\%) | 40 |
| Language 2 | 0 (0.00\%) | 5 (14.71\%) | 16 (47.06\%) | 12 (35.29\%) | 1 (2.94\%) | 34 |
| Language 3 | 1 (5.88\%) | 2 (11.76\%) | 6 (35.29\%) | 5 (29.41\%) | 3 (17.65\%) | 17 |
| Language 4 | 0 (0.00\%) | 2 (33.33\%) | 2 (33.33\%) | 1 (16.67\%) | 1 (16.67\%) | 6 |
| Language 5 | 0 (0.00\%) | 1 (50.00\%) | 0 (0.00\%) | 1 (50.00\%) | 0 (0.00\%) | 2 |
| Language 6 | 0 (0.00\%) | 0 (0.00\%) | 0 (0.00\%) | $1(100.00 \%)$ | 0 (0.00\%) | 1 |
| Communication |  |  |  |  |  |  |
|  | more than ageappropriate | ageappropriate | less than ageappropriate | much less than ageappropriate | not at all | total <br> (n) |
| Language 1 | 4 (25.00\%) | 2 (12.50\%) | 3 (18.75\%) | 3 (18.75\%) | 4 (25.00\%) | 16 |
| Language 2 | 0 (0.00\%) | 1 (8.33\%) | 5 (41.67\%) | 3 (25.00\%) | 3 (25.00\%) | 12 |
| Language 3 | 0 (0.00\%) | 0 (0.00\%) | 0 (0.00\%) | 1 (20.00\%) | 4 (80.00\%) | 5 |
| Language 4 | 0 (0.00\%) | 1 (100.00\%) | 0 (0.00\%) | 0 (0.00\%) | 0 (0.00\%) | 1 |
| Language 5 | 0 (0.00\%) | 1 (100.00\%) | 0 (0.00\%) | 0 (0.00\%) | 0 (0.00\%) | 1 |
| Language 6 | 0 (0.00\%) | 0 (0.00\%) | 0 (0.00\%) | 0 (0.00\%) | $1(100.00 \%)$ | 1 |

## Appendix $\mathbf{N}$

## Means and standard deviations

|  | $N$ | Mean | Std Dev | Std Err | Minimum | Maximum |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| How well does your child understand and communicate in each language used at home (in Q16)? Language 1 Understands | 40 | 3.6000 | 0.9819 | 0.1553 | 2.0000 | 5.0000 |
| How well does your child understand and communicate in each language used at home (in Q16)? Language 1 Communicates | 16 | 2.9375 | 1.5692 | 0.3923 | 1.0000 | 5.0000 |
| 2 or more languages Understand | 60 | 2.7000 | 0.9076 | 0.1172 | 1.0000 | 5.0000 |
| 2 or more languages Communicates | 20 | 2.1500 | 1.1367 | 0.2542 | 1.0000 | 4.0000 |
| How well does your child understand and communicate in each language used outside the home (in Q24)? Language 1 -Understands | 39 | 3.2308 | 1.0121 | 0.1621 | 1.0000 | 5.0000 |
| How well does your child understand and communicate in each language used outside the home (in Q24)? Language 1 - Communicates | 14 | 2.6429 | 1.5984 | 0.4272 | 1.0000 | 5.0000 |
| 2 or more languages Understand (outside the home) | 71 | 2.6620 | 1.1332 | 0.1345 | 1.0000 | 5.0000 |
| 2 or more languages Communicates (outside the home) | 25 | 2.2400 | 1.3626 | 0.2725 | 1.0000 | 5.0000 |
| It is important for my child with ASD to be bilingual | 38 | 3.8947 | 1.1099 | 0.1800 | 1.0000 | 5.0000 |
| Answer this question if you have another child(ren) without ASD. It is important for my child(ren) without ASD to be bilingual | 10 | 3.8000 | 0.4216 | 0.1333 | 3.0000 | 4.0000 |
| With what statements do you agree? Bilingualism is important for my child with ASD because it improves the following: Communication with family members | 38 | 3.7895 | 1.1427 | 0.1854 | 1.0000 | 5.0000 |
| Communication with people in your country of residence | 38 | 3.7895 | 1.1891 | 0.1929 | 1.0000 | 5.0000 |
| Communication in school/kindergarten | 38 | 3.7895 | 1.2554 | 0.2037 | 1.0000 | 5.0000 |


| Life opportunities <br> Future employment | 38 | 4.1579 | 1.0007 | 0.1623 | 1.0000 | 5.0000 |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Answer the following question <br> only if you have another <br> child(ren) without ASD: With <br> what statements do you agree? <br> Bilingualism is important for <br> my child without ASD because <br> it improves the following: <br> Communication with family | 27 | 3.7895 | 1.0694 | 0.1735 | 1.0000 | 5.0000 |
| members <br> Communication with people in | 27 | 1.0860 | 0.2090 | 1.0000 | 5.0000 |  |
| your country of residence | 27.9630 | 1.1596 | 0.2232 | 2.0000 | 5.0000 |  |
| Communication in <br> school/kindergarten | 27 | 3.9630 | 1.1596 | 0.2232 | 2.0000 | 5.0000 |
| Life opportunities | 27 | 4.2222 | 1.0127 | 0.1949 | 1.0000 | 5.0000 |
| Future employment | 27 | 4.1481 | 1.0635 | 0.2047 | 1.0000 | 5.0000 |
| Have any of the following <br> potential obstacles concerned <br> you in regard to your child <br> with ASD and learning other <br> languages? Learning <br> additional languages is too <br> hard for my child <br> There is not enough <br> professional help for my child <br> I cannot help my child learn <br> another language | 38 | 2.8947 | 1.3713 | 0.2225 | 1.0000 | 5.0000 |
| I am afraid my child will <br> become less fluent in their <br> native languages) <br> I am afraid my child will <br> become confused by two/more <br> languages <br> I do not have access to services <br> that can help my child with <br> bi/multilingualism <br> My family and/or friends will <br> not support my decision <br> I am not sure if it is better to <br> focus on one language | 38 | 38 | 38 | 38 | 38.5526 | 1.0000 |


[^0]:    ${ }^{1}$ This thesis uses the term "bilingualism" when referring to both bilingualism and multilingualism, it includes both sequential, simultaneous, balanced, and unbalanced bilingualism.

[^1]:    ${ }^{2}$ https://techandsciencepost.com/news/science/bilingualism-as-a-natural-therapy-for-autisticchildren/
    ${ }^{3} \mathrm{https}: / /$ medicalxpress.com/news/2021-06-bilingualism-natural-therapy-autistic-children.html
    ${ }^{4}$ https://autism-bilingualism.github.io/resources/

[^2]:    ${ }^{5}$ Translation: "Today is (DATE). My name is (NAME) and I consent to participate in this interview. I understand that I can pause and stop participating in this interview at any time."

[^3]:    ${ }^{6}$ While I specified that sign languages should be included with spoken languages, I decided to include it in alternative communication as well. Pilot tests showed that many people use definitions such as "gestures" and "sign language" interchangeably.

[^4]:    ${ }^{7}$ Languages in italics can be heard at home, but are not used by parents with their autistic children
    ${ }^{8}$ Anton was in the process or receiving an official diagnosis at that time
    ${ }^{9}$ Fredrik is not included into the final analysis; however, it would be very interesting to investigate FLP in families with now adult autistic people

[^5]:    (Q: So, we've talked a little bit about some of these negative aspects. And what about the benefits, the positive aspects of living in a multilingual environment for autistic children, do you see any benefits, so to speak?) Well, an extra language is always a plus, anyway. Wherever you go, whatever you do. Learning. That is available to children in many languages. It might be more difficult with an autistic person. But I don't think there will be one language, there will be at least two - we'll pull it out. I mean him. I was told, by the way, to take away the

